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ABSTRACT

This bulletin focuses on family participation in mental health policymaking and highlights state efforts to increase family involvement. Articles include: (1) "Promoting Family Member Involvement in Children's Mental Health Policy Making Bodies," which describes how different states are promoting family member involvement in various statutory and policy schemes; (2) "Partners in Policymaking: Far More than the Object of Policy," which provides quality principles for evaluating programs; (3) "Social Security Administration Reviews Closed Cases for Children with Disabilities"; (4) "Family Advocacy Coordinators: Evolving Roles in Colorado's System of Care"; (5) "Hawaii Federal Court Consent Decree Mandates Consumer and Family Member Participation in Policymaking"; (6) "Child and Adolescent Local Area Networks of Care in Illinois"; (7) "Partners at the Policy Table," which describes efforts in Massachusetts to involve parents in public policy discussions; (8) "Rhode Island's Efforts To Promote Family Member Participation in Policymaking"; (9) "Family Member Involvement in Policymaking in Vermont"; (10) "Family-Professional Relationships: Moving Forward Together: A Summary of the National Peer Technical Assistance Network's 1998 Publication"; (11) "1998 Building on Family Strengths Conference Held in Portland"; and (12) "EAT PYE: Youth Participation in Policymaking". The bulletin closes with a list of publications on family participation and advocacy. (CR)

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Family Participation in Policymaking

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EC 306 740

FOCAL POINT

A NATIONAL BULLETIN ON FAMILY SUPPORT & CHILDREN'S MENTAL HEALTH

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FAMILY PARTICIPATION IN POLICYMAKING

PROMOTING FAMILY MEMBER INVOLVEMENT IN CHILDREN'S MENTAL HEALTH POLICYMAKING BODIES

Much of the family member involvement that is happening at the state and local level is due, at least in part, to the efforts by the federal government to institutionalize family involvement in policymaking. In 1985 Child and Adolescent Service System (CASSP) staff added a family goal to the program. This goal translated into a requirement that state applications for CASSP funds describe how families would participate in service planning efforts at the child and family, program, and system levels. In 1986 Congress passed the State Mental Health Services Comprehensive Plan (Public Law 99-660), which mandated family member participation in the development of state mental health plans. Public Law 99-660's mandate continues today through the Alcohol, Drug Abuse and Mental Health Administration Reorganization Act (Public Law 102-321).

Family involvement is also a key component of federally-funded early intervention services to infants and young children who have disabilities or are at-risk of developmental disabilities (Public Law 99-457; Public Law 105-17). Further, with respect to special education, direct involvement of family members is required in the development of individualized education plans (IEP's) for their children (Public Law 94-142; Public Law 101-476; Public Law 105-17). The progress made-pursuant to federal mandates-to ensure consumer and family member participation in children's policymaking continues to

vary widely across states and among areas within states. This issue of *Focal Point* examines family member and consumer participation in children's mental health policymaking at state, regional and local levels. Here, too, we report upon the work of the Research and Training Center's *Family-Centered Policy: A Study of Family Member Representation at the Policy Level* project.

The findings presented by the *Family-Centered Policy* project are based on research done over the past four years. Data were collected via a telephone interview conducted with at least one representative from each state's department of child and adolescent mental health and a representative from each state's statewide family advocacy organization. The protocol for this interview was open-ended in nature and focused primarily on identifying any written policies, administrative rules or bylaws that existed in that state that mandated family member participation in policymaking. Copies of the policy document were then obtained and reviewed with regard to the language

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PARTNERS IN POLICYMAKING: FAR MORE THAN THE OBJECT OF POLICY

For those of us who remember it, diagramming sentences for grammar class was a laborious task. Most times it went like this: pick out the subject, pick out the verb, see if there is an object. Basically you tried to answer the question "Who did what to whom?" Sometimes, analyzing public policy can be the same way. People with disabilities and their families all too often are the objects of policies instead of helping to set the rules (either legislated or agency-set) that govern their lives. In 1987, an idea was developed in Minnesota to rearrange the parts of the policy sentence. "Partners in Policymaking" was designed to provide leadership training to parents of young children with disabilities and adults with disabilities. The program has been replicated in over forty of the United States and in the United Kingdom. The lessons and values of the program have applications across social policy areas and across oceans.

WHAT IS PARTNERS IN POLICYMAKING?

Partners in Policymaking is a leadership training program that teaches what works in disability services and supports to the people who have the most experience with what is needed in systems change - individuals with disabilities and parents of young children with disabilities. This hard-won expertise, combined with the policy

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We invite our audience to submit letters and comments.

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PROMOTING FAMILY MEMBER INVOLVEMENT CONTINUED

used. The study's two major goals were to identify what kind of policy instruments were being used to mandate family member participation in policymaking and to assess the language used to define which family members were considered eligible.

The policy instruments identified in the course of this research project *(Figure 1)* share the common feature of promoting or requiring family member or consumer participation in children's mental health policymaking activities. There are, however, different motivations expressed for the creation of these policy instruments. Arguably, **written policy guidelines** established at the agency or organizational level reflect "street-level" buy-in by agency administrators. The very administrative personnel who created the written policy guidelines are often the same individuals who will serve on the board or committee with family member representatives. The two will likely sit elbow-to-elbow at the policymaking table. Similarly, when an agency launches a policymaking body and establishes bylaws for the organization, that, too, reflects the agency's commitment.

At the next level, **administrative rules** reflect the will of state agency level personnel. An administrative rule is an official mandate or directive drafted and issued by a governmental agency. A state agency's authority to issue administrative rules is granted by statute by the state legislature.

Statutes are the mechanism used to promote family member involvement in policymaking that was most often identified in the course of this study. At this level, statutes reflect the will of the state legislature and, typically, they reflect the will of family members of children with serious mental, emotional or behavioral disorders who have lobbied the legislature on behalf of their children. Vermont is a leading example of a state in which family member participation has been a cornerstone of children's

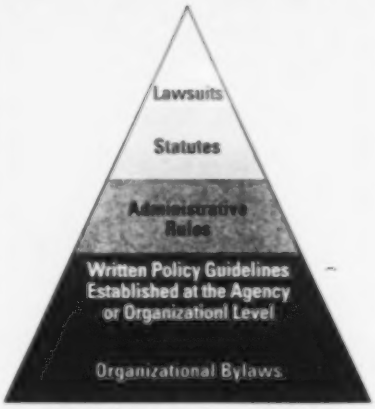


Figure 1. *Policy instruments identified in this project*

mental health decisionmaking from the very beginning. That state's Act 264, described on page 20, mandates parent involvement at *all* levels of decisionmaking. As one Vermont respondent stated, "It is virtually unheard of not to include parents in children's mental health planning. It's become a way of life."

Lawsuits are, of course, the most "top-down" vehicle for securing family members a seat at the decisionmaking table. At this level, typically, children with disabilities are class action plaintiffs and state agencies and state agency directors are the named defendants. From the perspective of the defendants, lawsuits are, without doubt, the most coercive method for securing family members a seat at the decision-making table. As contrasted with the relative harmony promoted by agency level policy guidelines or bylaws, acrimony may well divide state planners or policymakers from family advocates who are embroiled in a lawsuit. Conversely, state officials may whole heartedly agree with the plaintiffs and quietly support a lawsuit as the only vehicle that will successfully "get the attention" of legislative appropriations committees.

Most states reported having legislation that required family member or consumer involvement in governing bodies at state, regional or local levels. Thirty-one states reported at least one piece of such legislation and seven states reported that they had passed more than one. Seven states reported that they had developed administrative rules that supported family member involvement and two states were functioning under requirements laid down by lawsuits. Eleven states reported that they had developed a combination of policy instruments that supported family member participation, most typically this included legislation supported by written policy guidelines or administrative rules.

Our analysis of the policy instruments identified focused primarily upon answering the question, "Who serves?" In addition to various named officials-such as the heads of the departments of education, child welfare, mental health, juvenile justice, special education-the present study identified a variety of "categories" of individuals who serve on children's mental health policymaking bodies. There are four levels of family member involvement set forth in the various statutory and policy schemes.

Consumers. Four states (by statute in Connecticut, New Mexico, Minnesota and by a policy guideline in Illinois) have provisions that ensure that youth (or former youth) consumers of children's mental health services will have the opportunity to participate in policy development decisionmaking. These statutes are particularly exciting because they go to the very core of what representation is about. The most fundamental participation in the area of children's mental health requires that youth and youth consumers have a seat at the policymaking table.

Family members. Fifteen states specifically identify involving *family members whose children have mental, emotional or behavioral disorders.* With the exception of Illinois, statutes are the vehicles used in each state to promote or require family member involvement in children's mental health policymaking. Unlike legal changes

brought about by lawsuits, legal change brought about through legislation reflects that there is a growing public consensus about the rightness of a particular course of action. By their very nature, statutes reflect a significant community "buy-in" to the topic of the legislation.

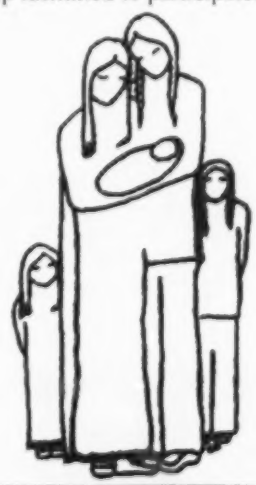
Ten states have statutes that specifically identify participation by *family members of children* in policymaking. While these statutes include children with mental or emotional disabilities, their scope is much broader. For example, as the appointing authority to the Maine Advisory Committee on Children with Special Needs, the Governor "shall give due consideration to including parents or relatives of children in need of treatment." (*Maine Revised Statutes Annotated 6241*) Thus, the individuals serving on Maine's Advisory Committee on Children With Special Needs will likely include family members of children with a broad range of physical disabilities as well as representatives of families whose children have mental health disabilities.

Those statutes that encourage or require the inclusion of *"families of persons with mental illness" (Colorado Revised Statutes 27-10-129) or "family members of consumers" (Virginia Code 37.1-195)* constitute the broadest category of family member representation and are the most vague. Accordingly, family advocates for children with mental health disabilities may cite such statutes as authority that they are entitled to serve on the particular board or committee. They may argue, for example, that as the legislature did not specify family members of adults only, it was the legislature's intention to be broadly inclusive.

Advocacy Organizations. Some state policies address-not individual family member participation-but involvement by representatives appointed by advocacy organizations. The language employed ranges from the very general ("at least one representative of an advocacy group for children with emotional disturbances," *Minnesota Statutes 245.697*) to the very specific. A Mississippi statute requires, for example, that an additional representative on the Mississippi Children's Advisory Council "shall be a family member designated by Mississippi Families as Allies, Inc., which is a nonprofit statewide advocacy organization that has a major focus on this population" (*Mississippi Code Annotated 43-14-1*).

While the Mississippi statute recognizes the statewide advocacy organization's well-deserved, very favorable national reputation, it unduly limits access to participation. While the council will hear the named organization's perspective, there is no assurance that other organizations-who may have very different agendas than the named organization-will have the opportunity to be heard. With respect to participation by representatives of children's mental health family advocacy organizations, more general language is preferable.

People of Color. Seventeen states have written mandates requiring policymaking bodies to include representatives of people of color. Most of these statutes are similar to that of the State of New Mexico. The membership of the New Mexico Children, Youth and Families Advisory Committee must "provide adequate representation of ethnic groups" (New Mexico Statutes Annotated 9-2a-12). Only five states specify a particular population of color and, in every instance, Native Americans are the group identified to participate.



Other Criteria. A few states have statutes that require geographic, economic and/or proportional gender representation on children's mental health policymaking bodies.

COMPENSATION. Typically, private individuals serving on children's mental health policymaking boards or committees receive no compensation for the time they invest in this work. They are, however, often compensated for their out-of-pocket expenses such as food, lodging and travel. For example, North Carolina provides that area board members "may receive as compensation for their services per diem and a subsistence allowance for each day" and "may be reimbursed for all necessary travel expenses and registration fees" (*North Carolina General Statutes 122C-120*). In fact, family members should be compensated for their time. A commitment to pay family members for their time truly reflects the goal of working partnerships with families. Professionals' salaries compensate them for their committee work, so, too, should family members be compensated for their participation. Florida is noteworthy for its provision authorizing payment "for preapproved child care expenses or lost wages for members who are consumers of the department's services" (*Florida Statutes 20.19(7)(g)*).

TRAINING AND RECRUITMENT. A few states do mandate training for new board members. North Carolina, for example, provides that all members of an area authority's board of directors "shall receive initial orientation on board members' responsibilities and training...in fiscal management, budget development, and fiscal responsibility" (North Carolina General Statutes 122C-119.1). Recruitment is delegated to statewide family organizations in many states. In twenty-four states, both family representatives and state mental health staff agreed that the family organization had been given the responsibility for identifying family members who would like to serve as members of boards and committees. The fam-

ily advocacy organization receives money to do this outreach in fourteen states.

LAWSUITS. Litigation is the remaining key vehicle for promoting or requiring family member participation in children's mental health policymaking. Lawsuits are extremely expensive and should only be pursued after all other efforts have failed. Most notably, in 1993 a class action lawsuit, *Felix v. Waihee*, was filed in United States District Court (Hawaii). As Lavernne Nakamura's article, on page 11, explains, negotiations among the parties led to the entry of a Consent Decree and a subsequent Implementation Plan.

Felix v. Waihee represents the most comprehensive court-mandated effort to date to require consumer and family member participation in policymaking activities. The lawsuit resulted in the creation of a Community Children's Council (CCC) for each of the state's geographic areas as well as the creation of the State Children's Council. *Felix v. Waihee* requires: (1) At least one-third of the members of each Community Children's Council must be direct consumers or family members; (2) The remainder will represent education, mental health, and other service providers; and (3) each CCC shall elect a professional and a family member to the State Children's Council.

CONCLUSION. Managed behavioral health care is increasingly becoming the norm for public and private mental health systems. The policy documents identified in the Family-Centered Policy project's study that reflect the movement towards consumer and family member participation in policymaking, are readily transferable to managed behavioral health care policies and practices. Children's mental health policymaking in the managed behavioral health care arena requires that, among others, youth consumers, family members of child and adolescent consumers, people of color, and advocacy organization representatives have a seat at the table. And-in honoring these individuals for their time and their contributions-they will receive appropriate training, support and compensation.

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SOCIAL SECURITY ADMINISTRATION REVIEWS CLOSED CASES FOR CHILDREN WITH DISABILITIES

The Social Security Administration (SSA) is currently conducting reviews of the changes in the Social Security Income (SSI) childhood disability program which were included in the welfare reform law of 1996. The welfare reform law makes eligibility requirements stricter, and as a result SSA estimates that approximately 100,000 children with disabilities will lose (or have already lost) their benefits.

A review completed in December of 1997 indicated that there were three key areas of concern: children classified as having mental retardation, children with cases closed due to the caregiver's failure to cooperate, and a lack of clarity regarding the right to appeal SSA decisions. The study found that some children with mental retardation were having their benefits stopped because of reviewer errors, such as failing to look at all information and not considering the range of error in all test results. As a result of this finding, Social Security Commissioner Kenneth S. Apfel ordered the reevaluation of all cases in which benefits were stopped (or new applications denied after the passage of the welfare reform law) to children with the classification of mental retardation. These reviews began at the end of March of this year.

Additional errors were found in cases in which benefits were ceased due to the failure of the caregiver to cooperate. In these cases, a caregiver failed to take their child to a medical examination or did not respond to notices from SSA. The review, however, found that in some cases not all of the proper contacts were made with the caregiver before the benefits were ceased. Commissioner Apfel has initiated a review of all of these cases as well to make sure that SSA made every effort to contact the caregiver.

Another area of concern was in the notification of the rights of caregivers. The review found that many parents did not understand that they had the right to appeal when benefits were stopped and the right to request that benefits continue while SSA reconsiders their case. As a result of this finding, new notices with clearer language as well as notification of legal resources were sent to parents in February 1998.

For more information, please contact the SSA at 1-800-772-1213.

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FAR MORE OBJECT OF THAN POLICY CONTINUED

tools and strategies that the program presents, are the best formula for ensuring a vision for the future. This vision focuses on the independence, integration, inclusion and productivity of people with disabilities in their communities. The program is typically run or funded by a state developmental disabilities council or funded by a private foundation.

The program has 128 hours of instruction provided over eight weekends, with one weekend session each month. This time commitment ensures that Partners "learn how to learn." "What works" (also known as best practices) is a moving target. Continuous improvement of processes means that a person simply cannot any longer keep applying the same model indefinitely. The topics of the Partners programs are general enough so that continuous learning is the aim of the session, not acquiring any specific set of knowledge. The time period between each session ensures that Partners get a chance to practice their skills through homework assignments and incremental work towards the completion of a major public policy project.

WHY DID IT COME ABOUT?

In 1987, Colleen Wieck, Executive Director of the Minnesota Governor's Council on Developmental Disabilities and Ed Skarnulis, Director of the Developmental Disabilities Division at the Minnesota Department of Human Services, were struck by the leadership vacuum among young parents and people with disabilities (self-advocates). The average age of members of national associations on developmental disabilities was creeping steadily upwards. Few if any self-advocates were involved in setting direction for these organizations. The need for parents and self-advocates to learn how to make effective systems change was evident. The gains of the disability movement were at stake.

WHAT ARE THE QUALITY PRINCIPLES OF THE PROGRAM?

In order to ensure that the program meets its ultimate outcomes (independence, inclusion, integration and productivity for all Partners and their family members), the design of the program built in quality principles that served this end:

Experiential Learning: Partners learn by doing. They prepare and deliver testimony to public officials or their representatives. They practice catching public officials in the hallway and getting their stand on an issue across in a few minutes. Both parents and self-advocates benefit from the experience of the other group. They use a variety of different learning methods to acquire a very specific set of competencies.

Diversity: Partners groups are diverse in experiences, disability types, geographic location, gender, racial and ethnic backgrounds, income levels and education levels. Partners learn as much from the experiences of others as from the curriculum.

National Speakers: Partners obtain training from speakers who provide a national perspective. These speakers are not inhibited by their roles in the state where the program is operating - either they are from outside the state or their job in the state is to make these specific types of changes.

Best Practices: Partners learn about what is possible, not about the current system of services and supports in their state or locale which they already know about. They break out of the status quo and ask "What if...?"

Leadership: Partners acquire knowledge not just for the sake of knowledge. They take things they learn and take action for social change. They provide leadership for their communities. The program is not about getting the most services for themselves and their families; rather, it is about getting what they need and making sure others have the same opportunity.

Length of Time: Funders make a commitment to the Partners programs for a full eight training sessions. Partners receive 128 hours of instruction over the course of a program year.

Sufficient Funding: Funders commit to quality replications that pay for all program-related expenses (meeting space, meals, accommodations, respite and child care, and travel expenses). This money supports the other quality principles. Without addressing these concerns, Partners cannot take the first step toward participating.

Evaluation: Partners and speakers evaluate their experiences with the program. A baseline survey is taken of Partners when they start the program. They are surveyed again six months following graduation with follow up surveys thereafter. These results are tracked and monitored for long-term trends. Changes in the program are implemented based on these assessments.

Not an Organization: Partners is a training program - the real work of graduates is in the community, state and national organizations. The program links them with networks and helps them acquire the competencies needed to succeed. No national database of Partners exists. An individual cannot pay money to join. After committing to the program and following through with attendance and hard

BAZELON CENTER CREATES "ADVANCE DIRECTIVES"

The Bazelon Center for Mental Health Law has created a document which mental health patients can use to indicate what treatments they do not want to have if they are involuntarily committed. On this document, the patient can also indicate who they wish to select to make their mental health decisions, such as a family member or a friend. The advanced directive form can be obtained for free on the Bazelon Center's web-site: www.bazelon.org/advdir.html

For more information, contact Bazelon Center at (202) 467-5730.

work, an individual becomes a Partner and goes on to change the world.

WHAT ARE THE VALUES BY WHICH THE PROGRAM JUDGES ITSELF?

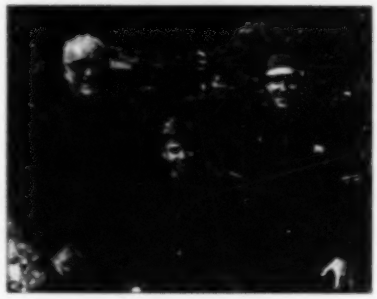
A quality Partners in Policymaking program is built on the inherent human rights and responsibilities of people with disabilities. Every aspect of the training program must reflect these values, otherwise the program is not living up to the funding source's expectations or the quality principles.

People with disabilities are people first. The disability should come second, if at all. Labeling goes against the program's purpose - to promote best practices in disability services. If best practices are always changing, giving someone a static label by which their life is defined will be ineffective at best and highly damaging to the person's ability to define his or herself at worst.

People with disabilities need real friendships, networks and bonds, not just relationships with paid staff. In this way, all Partners are entitled to establish the connections with each other and policymakers that they need to succeed at making systems change.

People with disabilities must be able to enjoy full mobility and accessibility that allows active participation in community life. This includes physical accessibility but goes beyond it. Learning methods and program materials must be modified so that everyone has a fair shot at attaining the skills they need as systems change advocates.

Continuity in the lives of people with disabilities is extremely important. This continuity takes place though families and neighborhood connections. Partners programs reflect this need. Again, Partners is not an organization to which people belong or do not belong based upon membership dues or other signs of allegiance. It is a continuous presence in the lives of people who have gone through the program, providing the support and tools people need to achieve their personal and systems' change goals.



Dignity and respect for people with disabilities is critical. How can a person expect to succeed at changing policy and systems for the better if they cannot respect the other people who are similarly promoting change and who will benefit from such changes? This also means that Partners are encouraged to respect themselves and their experiences in ways that they may not have before. People with disabilities must be in positions to negotiate to have their wants and needs met. These positions may be informal, like serving as an on-call advisor for a policymaker who respects and needs the opinions of a person with experience on disabilities issues. These positions increasingly have become more formal, with Partners graduates taking on policymaking roles as elected and appointed officials at local, state, and national levels.

Choice is critical for people with disabilities in all areas of their lives. These choices are neither more nor less than the rights people with disabilities have. People with disabilities must be able to live in the homes of their choice with the supports they need. Institutions and other settings with large numbers of people living together without input into their living arrangements are antithetical to best practices in disability services.

Productivity through employment or contributions as community members are both the right and the responsibility of people with disabilities. People with disabilities work and succeed in competitive employment when this responsibility is recognized by employers.

WHAT DOES THE PROGRAM'S CURRICULUM LOOK LIKE?

National speakers provide the training. Logistical and program arrangements are made by a coordinator. The program covers two broad topical areas.

Life area topics give Partners details on the best delivery practices. For example, an inclusive education expert explains what works with children and young adults in classrooms. The other life area topics are assistive technology and positioning, competitive employment, independent living and a home of your own.

Policy and systems topics introduce Partners to working with federal, state, and county officials. They learn how to access policymakers through writing letters and providing testimony. These tools are effective and proven strategies that build systemic change possibilities. Community organizing is a critical skill Partners learn. Parliamentary procedure is also covered, with emphasis on both learning how to follow a meeting in which these rules are used and learning how to use the tools for the meetings that Partners will lead themselves.

Partners learn through role playing, group activities and small group discussions. They practice giving testimony before actual legislators and their staff. They discuss issues and concerns directly with state agency employees in a neutral setting. Homework is assigned and partners report back on their experiences and impressions so that a multiplier occurs - Partners both gain perspective on how the system works and are exposed to others' perspectives. Partners get practice at doing what they continue to do after graduation - advocating on behalf of themselves and their families.

HOW DO PROGRAMS ENSURE THAT COMPETENCIES ARE MET?

In Partners programs, there is a three-prong approach to ensuring quality improvement. First, long-term evaluations are conducted by exter-

nal evaluators to compare the activity levels of Partners at a baseline before the program, six months after the program and for up to five years thereafter. Surveys mailed to Partners typically have a high return rate. The results are tabulated and analyzed for program improvements.

Second, program coordinators evaluate themselves and are evaluated by the funding source. Most programs evaluate quarterly. This frequency allows programmatic and logistical issues to be corrected quickly and to the greatest effect for participants.

Third, Partners evaluate presenters after each session. The program coordinator takes these suggestions and adjusts program logistics before the next session as needed. Comments on presenters are used to determine who will present the topics for the next class.

WHAT HAPPENS TO PARTNERS ONCE THEY COMPLETE THE PROGRAM?

Partners become systems change advocates. They use the skills and abilities they have developed to influence policies to make the lives of people with disabilities better. A few Partners graduates have served as Kennedy Fellows in the United States Senate. These people provide the Senate committees that address disabilities issues the critical expertise they need from people who know how the system works and how to make it better. Several Partners graduates have been elected to local and state positions. Many more have been appointed to boards and commissions that directly set the terms of debate for disability policy. Perhaps most profoundly, there are literally thousands of people in the United Sates and the United Kingdom who share the same expertise and are able to make their own lives and the lives of others better.

Many states provide Partners with funding for continuing education or opportunities to learn new skills as they go through their systems change activities. These supports are an important refresher that help individuals continue to be effective.

WHERE HAS PARTNERS BEEN REPLICATED?

Partners programs are currently operating or being planned in forty-two of the United States and Territories. Three states and territories are considering operating the program in the future. Just four states and the District of Columbia have never operated the program. There are six sites in the United Kingdom that are in the planning or operating phase. A program has been funded by UNICEF to begin in the Philippines. To learn more about Partners in Policymaking in your state or territory, or to get additional information on the program, please contact either of the authors at:

TARA BARENOK & COLLEEN WIECK, PH.D., *Governor's Council on Developmental Disabilities, 300 Centennial Office Building, 658 Cedar Street, St. Paul, Minnesota 55155; (612) 296-4018 (voice); (612) 297-7200 (fax); email: admin.dd@state.mn.us or tara.barenok @state.mn.us; Web site: http:// www.thirdageinc.com/mddc*

FAMILY ADVOCACY COORDINATORS: EVOLVING ROLES IN COLORADO'S SYSTEM OF CARE

Family involvement is a central value of the system of care philosophy. However, making this a reality in states and communities represents a significant challenge. In addition to ensuring that families participate fully in services for their own children, it is essential to hear their voices at all levels of planning and policy development. Colorado has strengthened family involvement at the local and state levels through developing Family Advocacy Coordinators, also referred to as Family Advocates, who work in an array of agencies and environments.

These paid positions operate on the premise that family-to-family methods of providing support and advocacy are a necessary complement to formal services. Family Advocates typically are parents or family members of children or adolescents who are at risk or are current or former consumers of some aspect of the local service system. From the outset, they have operated on the belief that a partnership between families and service providers is an essential aspect of a system of care. The approach assumes the need to have families represented in policy and service development, and emphasizes organizing family support and advocacy networks.

This effort began at the state mental health level, and later moved into local communities through the mental health, juvenile justice and child welfare systems. The Family Advocates have had a profound effect on each of the systems, agencies, and communities in which they operate. Integrated with interagency councils and service coordination teams, their roles have evolved over time and been modified based on community needs, values, and resources.

STATE LEVEL DEVELOPMENT

Supported through a federal Child and Adolescent Service System Program (CASSP) grant, Colorado Mental Health Services (MHS), the state mental health agency, first established a state-level Family Advocacy Coordinator. This paid position, based at the Mental Health Association of Colorado, focused on providing support, advocacy, and education for parents and families. Much of this work involved organizing parents at the local level through community forums, sponsoring state conferences, and providing support and advocacy to parents and families in accessing services.

The Family Advocacy Coordinator also served on the state CASSP Advisory Council, which provides overall guidance and policy recommendations regarding system of care development. Possibly the most important function of this position was modeling how families could be a positive force in shaping policy and practice in children's mental health at the state and local levels. As a result, there is now a Colorado chapter of the Federation of Families for Children's Mental Health.

MENTAL HEALTH

The successes of the state Family Advocacy Coordinator soon led to the realization of the need for similar community-based positions. A second CASSP grant provided the opportunity for MHS to develop the role in local systems of care. Using community mental health centers as the base of operations, the project funded Family Advocacy Coordinators in three communities including urban, suburban, and rural sites.

Communities make use of the Family Advocates in different ways, depending on local priorities. Activities include attending Individualized Education Program meetings, developing support groups, and providing individualized supports to families. One community located their Family Advocate at a family resource center. As a result, she was highly accessible to families of children not involved in the public mental health system.

At the policy level, most local Family Advocacy Coordinators participate on local interagency councils and the state CASSP Advisory Council. On the CASSP Council they provide an invaluable family-focused viewpoint on policies and services, and keep others aware of new developments involving families in community-based services. As a tribute to the effectiveness of the Family Advocacy Coordinators, each position continued beyond the end of CASSP grant funding. In one locale, the host community mental health center has added an additional Family Advocacy Coordinator.

An informal survey pointed out some key issues that are important to consider in future development of mental health Family Advocates:

- Family Advocates who have children with mental health needs must be able to balance the demands of their own family with those of the families they serve; supportive agency environments are essential.
- Interagency councils and teams do not include families in all communities. There is a need to better understand agency and community readiness for full family involvement, and to develop strategies for addressing potential barriers.
- There continues to be a question about whether Family Advocates should be employed by service agencies or by family organizations. Understanding how family organizations and agencies can work collaboratively will help in resolving this issue.
- Family Advocates can be very effective when they work in nontraditional and informal ways to help families. A family-to-family approach can be very effective in wraparound services.
- Maintaining connections between local Family Advocates and state level supports is important. Family involvement requires consistent backing from both local and state policymakers.

A recent evaluation of Colorado's mental health managed care program suggests the availability of a Family Advocacy Coordinator favorably influences a family's perception that their child's service needs are met. Due to the recognition of the key role they serve, Family Advocacy Coordinators are being integrated into Colorado's Medicaid capitation program. The recent Medicaid capitation request for proposals requires that Family Advocates be established at Mental Health Assessment and Service Agencies, Colorado's managed care organizations. These Family Advocates will provide information and support to families and children served through the capitation system.

JUVENILE JUSTICE

The development of Family Advocacy Coordinators has also expanded to the juvenile justice system where there are significant numbers of youth in need of mental health services. The Colorado Division of Criminal Justice (DCJ), with support through the federal Office of Juvenile Justice and Delinquency Prevention, now funds Family Advocates in four communities. Collaborative efforts between DCJ and Colorado Mental Health Services allowed for joint development of the positions, and linking them with existing Family Advocates and training opportunities.

Involved communities include three in the Denver metropolitan area and a city in the western region of the state. Three of the Family Advocates work at community-based youth and family agencies and the other at a community mental health center. Due to the emphasis on increasing resources for minority youth and their families, Hispanic and African American Family Advocates have worked in these communities.

The juvenile justice Family Advocacy Coordinators participate on local interagency councils and service coordination teams focused on youth at-risk of involvement in the court, probation, and youth corrections systems. Additionally, they do a considerable amount of work with other

community agencies such as schools, home visitor programs, and culturally oriented organizations. Efforts of the Family Advocates involve diverse strategies to increase family involvement. These include increasing parent participation on interagency teams, sponsoring family support and education teams, advocating for youth in court, providing case management services, and organizing groups for children in elementary and middle schools.

Much of the work of the juvenile justice Family Advocates aims at preventing children from becoming involved in youth corrections. In some communities there are considerable school-based services facilitated by Family Advocates, including family and youth support groups. In one community, parents of at-risk youth receive training to work as support group volunteers. Youth groups facilitated by Family Advocates cover diverse topics. These include conflict management, teen pregnancy, dropout prevention, career exploration, academic responsibilities, behavior responsibilities, and summer vacation planning.

One parent described her family's positive experience with a Family Advocate:

> *The Family Advocate did a great job by giving us emotional support and coordinated services for us at the beginning of our crisis, rather than later when they would not have been as effective. The Family Advocate points out the positives and gets parents involved. (Excerpt).*

CHILD WELFARE

Supported by state Child Welfare Services, Family Advocacy Coordinators work in communities funded by the federally sponsored Family Preservation and Family Support program. The child welfare Family Advocates work at various community agencies including family centers, schools, and other community-based agencies. Their efforts include assisting families in accessing a broad array of services that support at-risk families, providing education materials, and coordinating local family advocacy activities. In all, seventeen communities participate in this effort, with some areas having as many as five Family Advocates.

The child welfare Family Advocates work at various community resource centers including schools and family centers. In one community, a Family Advocate works on early childhood issues helping families of young children with special needs access services and supports. In conjunction with the STATES Initiative, a new Interagency Family Advocacy Curriculum will serve as a tool to increase skills and knowledge. The curriculum includes content on advocacy, family development, self-empowerment, group and community work, formal and informal support systems, and working with service systems. The first training session took place in November 1997.

CONCLUSION

Family Advocacy Coordinators have significantly changed the landscape of child and family services in Colorado. Possibly the most important lesson learned is how Family Advocates can increase the effectiveness of more traditional and formal methods of helping families. Key issues for the future include increasing Family Advocates' accessibility through normalized community-based locations, maintaining links with state and local policy and service councils, and connecting Family Advocates with managed care organizations. Also, there is a need to explore ways that Family Advocates can work in conjunction with family organizations.

The development of Family Advocates in mental health, juvenile justice, and child welfare is based not only upon a recognition of their effectiveness. It also underlines the need for such family-focused resources and leadership across agency boundaries. Families of children with mental health needs often find themselves involved with various systems, or wondering where to access help. Family Advocates can offer a bridge for families needing information and a guide to help them obtain the supports they need. With Family Advocates working in partnership with community agencies, the goal of family involvement in Colorado becomes more of a reality.

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BAZELON CENTER PUBLISHES SSI BENEFITS BOOKLET FOR PARENTS

The Bazelon Center for Mental Health Law has recently published a handbook for families and advocates which explains the Supplemental Security Income (SSI) system and the process for qualifying for monthly cash benefits for children with severe mental and physical disabilities. The new 1996 eligibility rules as well as the process for appealing when benefits are denied are described in easy to understand language. The handbook is also available in Spanish. The cost is $3 plus $2 for shipping. To order this booklet, please contact the Bazelon Center at (202) 467-5730 or write them at:

Publications Desk, Bazelon Center for Mental Health Law, 1101 15th Street NW, Suite 1212, Washington DC 20005-5992.

THE CLEARINGHOUSE IS BILINGUAL

The Clearinghouse is pleased to announce that telephone assistance is available in both English and Spanish. Some written materials are also available in Spanish.

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HAWAII FEDERAL COURT CONSENT DECREE MANDATES CONSUMER AND FAMILY MEMBER PARTICIPATION IN POLICYMAKING

Hawaii Families as Allies (HFAA) is a non-profit, parent-run statewide organization as well as the Hawaii chapter of the Federation of Families for Children's Mental Health. HFAA is the only organization in Hawaii focused exclusively on the needs of children and youth with emotional, mental and behavioral disorders and their families. In fact, all of our staff are parents and/or foster parents of children with serious emotional disorders. HFAA has been known to families and professionals as an organization that supports collaboratively building systems of care which are child-centered and family-focused, culturally competent, coordinated, and community-based. Since 1988 HFAA has served as the statewide resource center for policy and technical assistance to improve service delivery and outcomes for children and adolescents with or at-risk of serious emotional disorders and their families.

In May 1993, a lawsuit was filed in United States District Court by seven parents on behalf of their children and 21 organizations statewide (including Hawaii Families as Allies). The lawsuit charged the State of Hawaii and its Departments of Education and Health with failure to provide educational and mental health services to children and adolescents with disabilities in accordance with the Individuals with Disabilities Education Act (IDEA) and Section 504 of the 1973 Rehabilitation Act. The lawsuit sought to represent children with disabilities who are eligible for and in need of educational and mental health services but for whom programs, services and placements were either unavailable, inadequate, or inappropriate because of the lack of a continuum of programs and placements which the State is mandated to provide through its agencies. Many envisioned that this lawsuit would alter the role of family involvement in policymaking—that Hawaii would revolutionize family-centered policy.

The State of Hawaii had a period of twenty days to respond to the complaint. However, even before its answer to the complaint had been filed with the Court, the State began settlement discussions with attorneys for the Plaintiff Class. In May 1994, both parties filed motions for summary judgment. The Court granted plaintiffs' motion (in part) and determined that the State of Hawaii and its Departments of Education and Health had "systematically failed to provide required and necessary educational and mental health services to qualified handicapped children of the State of Hawaii in violation of the Individuals with Disabilities Education Act and the Rehabilitation Act of 1973." *Felix v. Waihee, 1994*. This holding was based, in part, on the State's acknowledgement of deficiencies in the system of care.

In October 1994, the court approved a consent decree jointly drafted by the State and attorneys for the Plaintiff Class. Known as the *Felix Consent Decree*, the document set forth the terms and conditions of settlement intended "to ensure that the Plaintiff Class has available to them a free appropriate public education they are entitled to under IDEA and Section 504, and that a system of care which includes a continuum of services, placements, and programs following the principles of the Hawaii Child and Adolescent Service System Program (CASSP) is created for the Plaintiff Class." *Felix v. Waihee, Consent Decree 1994*. The consent decree further contemplates that "services will be child and family centered involving and consulting families in planning, evaluation, training, treatment, and support functions," and that "when necessary, services shall be provided to class members and parents to enable them to participate as partners. Such services shall include advance discussions, scheduling consideration, interpreter's services, assistance with understanding written materials, and other accommodations as needed." *Felix v. Waihee, 1994*.

In order to fulfill its obligations under the consent decree, the State agreed to develop a plan of operation that describes the specific design for the new system of care, and includes a specific schedule with critical milestones for implementing the design, known as the *Felix Implementation Plan*. The Implementation Plan, which was approved by the Court in October 1995, established:

1. **Community Children's Councils (CCCs)**
   - Community-based (16 CCCs statewide);
   - At least 1/3 direct consumers or family members;
   - Representatives reflective of a crosssection of community agencies, service providers, civic and religious groups;
   - Community participation in needs assessment, service system planning, budget recommendations and quality management activities;
   - Arena for child-serving agencies to integrate efforts in system development and service delivery;
   - Local forum for setting community-based priorities and planning;
   - Appoint representative(s) to State Children's Council (SCC)
2. **State Children's Council (SCC)**
   - Comprised of representatives of each CCC;
   - Integrate decisions and recommendations from CCCs into statewide plan to submit to Cabinet Level Council (CLC)
3. **Cabinet Level Council (CLC)**
   - Representatives of State departments to provide leadership;
   - Remove barriers to effective service delivery
4. **Operational Management Team (OMT)**

- Executive body with authority to manage and implement policies and recommend changes;
- Comprised of deputy directors, assistant superintendents, other administrators;
- Report to Director of Health and Superintendent of Education

5. Community Children's Council Office (AKA State Implementation Team)

- Provide technical assistance and support to CCCs and SCC;
- Oversee implementation of community and parent training;
- Coordinate staff training;
- Interface between CCCs, SCC, OMT and other State agencies in the preparation of the Executive Budget;
- Ensure parent participation in the above activities.

During Fall 1995, the "Together We Can" awareness training was offered in seventeen communities statewide. The training was intended to generate an "awareness" that educators and service providers needed to do things differently when working with youth with disabilities and their families, and that system reform occurs as individuals change, one person at a time. Each training was comprised of deliberately selected teams of facilitators and participants to model interagency collaboration and parent-professional partnership. Training sites closely matched the areas in which each CCC was to be established. Thus, after creating this awareness via a soft-sell approach to a gathering of community stakeholders, training participants were invited to attend the inaugural CCC meeting in their community. Several Hawaii Families as Allies staff and board members served as training facilitators, while others attended the trainings in their respective communities as family participants.

Since early 1996 the sixteen CCCs have been meeting to determine their composition and structure, establish their leadership, develop initial governing rules and local procedures, and set priorities for the activities they undertake. Their common vision is to design a system of care in accordance with the *Felix Consent Decree* and *Implementation Plan* which embraces the CASSP values and principles to more responsively meet the multiple and changing needs of youngsters in their community. While all sixteen of the CCCs have been operational, some have progressed more rapidly than others with regard to organization and composition, consumer/family involvement, leadership development, coalition building and consensus development.

Members of the Hawaii Family as Allies

Support from the State via the Community Children's Council Office (CCCO) as stipulated in the *Felix Consent Decree and Implementation Plan* has been fragmented and minimal. Although consumer/family participation has been a major concern for several of the CCCs, the training for "class members and parents to enable them to participate as partners" (*Felix v. Waihee*) has not occurred despite the offer made by Hawaii Families As Allies that it possesses the knowledge and expertise to conduct this training for the State. It did not take long for everyone to realize that-if working parents were expected to participate—CCC meetings could not take place during 9:00 A.M. to 3:00 P.M. banker's hours. It did, however, require many months of negotiating for parents to convince the State that families need reimbursement for childcare and other expenses to enable them to attend CCC meetings in the evening.

The lack of administrative support and technical assistance from the State has also left CCCs struggling to find ways to disseminate notices and information in a timely manner, or without the knowledge and means to conduct needs assessments. CCCs who are unable to determine community needs will find it difficult to do the service system planning, budget recommendations and quality management activities specified in the *Implementation Plan*. Families have invested a considerable amount of time and energy in CCC participation believing this is the vehicle for communicating their needs and improving services for their children. Unless the State takes the necessary steps to wholly support and empower the CCCs to accomplish the Implementation Plan goals and objectives, the spirit of the lawsuit will be left unfulfilled.

Based upon anecdotal information that we receive from families and others in the community, there remains an unwillingness by educators and other service providers to view parents as allies and equal partners in planning services for their children

with special needs and in the decision-making processes. Parents continue to attend meetings and are presented with prepared Individualized Plans (IEPs) or treatment plans with which they have had no input, but for which their approval is sought on the spot.

Two parents were invited by the State Department of Education (DOE) to participate on a panel to interview candidates for the position of state special education administrator. The identity of the candidates and the DOE's qualification requirements were withheld from the panel members until 30 minutes prior to the first interview. Each panel member was asked to select a single question (which was prepared by the DOE personnel office staff) to ask the candidates. The candidate who was finally selected vacated this position after six months, and his replacement was appointed by the Superintendent of Education—thus bypassing the interview process altogether.

The State Department of Health (DOH) is currently seeking yet another Chief for its Child and Adolescent Mental Health Division (CAMHD). Various consumer/parent and advocacy organizations received correspondence from CAMHD requesting them to come to a consensus among themselves regarding the nomination of ONE parent to serve on the interview panel for CAMHD Chief. They were informed that CAMHD reserved the right to accept or decline the parent nominated. The organizations were given one week to nominate the parent.

Last summer the DOE and DOH jointly drafted policies on the referral of students for IDEA/§504 evaluations and the responsibility and identification of care coordinators. Knowing that the CCCs meet monthly, the draft policies were distributed to each CCC for review and input due in two weeks. I know that my personal suggestions and recommendations submitted to DOE/DOH for consideration were not incorporated into the final policies. In fact, the final policies did not appear substantially different from the draft.

I also had the opportunity to participate in a work group during August and September that was directed to develop a single policy for care coordination that could be adopted by all state agencies that serve children. I suggested the policy state that when agency personnel are paid for their time, expertise and expenses, then family/community members who serve as care coordinators shall likewise be compensated. After all, the DOE already allows parents and community members to be volunteer care coordinators if they choose, and the IDEA amendments of 1997 support the concept of training and hiring paraprofessionals, especially in cases where professionals are in short supply. It generated some poignant discussion but, in the end, the agency personnel vetoed my suggestion.

Even before the State of Hawaii filed its answer to the *Felix v. Waihee* complaint, state administrators were aware things needed to be done differently when it came to educating students with disabilities. By entering into the *Felix Consent Decree* the State of Hawaii pledged its affirmative commitment to abide by the IDEA and Section 504 and to embrace the CASSP values and principles while providing educational and mental health services to students with disabilities. In the two years since the court approved the *Felix Consent Decree* there have been numerous community forums, school-level dialogues, and public access television productions that emphasized the need for meaningful parent participation, but the pace of system change has yet to meet the urgency of need felt by many parents whose youngsters have emotional and behavioral disorders. Linda Colburn, *Felix* Operations Manager, attributes our dilatory rate of progress in part to "institutional inertia"—several large systems (DOE, DOH, etc.), each with its unique characteristics, which are resistant to change.

From our standpoint, under the guise of embracing the CASSP values and principles and compliance with IDEA and Section 504, attempts by the State of Hawaii and its departments thus far to involve parents have been merely obligatory. Empowerment and full inclusion of families has not yet happened in a truly meaningful way. But as parents, we persevere — for our children and for the system of care that serves them.

LAVERNNE NAKAMURA, *Hawaii Families as Allies, 200 N. Vineyard, Suite 300, Honolulu, Hawaii 96817; (808) 521-1846 (telephone).*

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CHILD AND ADOLESCENT LOCAL AREA NETWORKS OF CARE IN ILLINOIS

In the Fall of 1993, the Department of Mental Health and Developmental Disabilities (DMHDD) undertook a major initiative to establish local areas and coordinating networks for children and adolescents (C&A) in need of mental health services. The director of the Department of Mental Health, Jess McDonald, developed the concept in partnership with the Illinois Department of Children and Family Services, the Illinois State Board of Education and parents of children with severe emotional disorders. The goal of the Local Area Networks of Care was to develop a unified, publicly-funded, community-based mental health service system within designated geographic areas of the state. Families then would be able to obtain services for their children in their own community, and service plans would shift from being agency-driven to family-driven. The State of Illinois was divided into 62 local area networks (LANs) and principles for the development of a C&A LAN were formulated.

The Steering Committee is the decision-making body of the C&A LAN. Membership consists of "stakeholders" or persons who have an interest in improving outcomes for children with serious emotional disorders. Membership includes mental health centers, child welfare agencies, special education directors, parents and foster parents, representatives from juvenile justice, substance abuse and public health. The steering committee was to reflect the culture of the community it represents. Most steering committees met monthly and the meetings were open to the public. Meetings were at times and locations convenient to the membership. In order for each community to reflect the stakeholders and needs of their community, (1) membership of the steering committee is not dictated by policy; and (2) each LAN is expected to identify stakeholders to bring to their individual tables. Each LAN has at least two co-

conveners (stakeholders responsible for conducting the LAN meetings) elected from the membership of the LAN. Since the beginning of the LAN movement, parents have an equal opportunity with agency members to sit as co-conveners, however in the past five years, only one LAN in Illinois has a parent who, in 1997, became a co-convener.

LANs also include flex fund committees. Most LAN's have one such committee, however, geographically larger LAN's have divided into as many as four flex fund committees. These committees decide the requests for flexible dollars used to provide community services for the child that are unavailable through traditional means.

The use of flex funds was critical in the plan for success in community-based systems of care. In order for a child to return home from a residential center, or in order to maintain a child in crisis in the community, often creative, non-traditional services were needed. Agencies and schools are tied to policy and program regulations and often cannot provide these unique or non-traditional services through their normal service provision. Flex funds were made available in order to assure that all service needs could be met in the community.

Flex funds are the result of pooled public funding with contributions from the Department of Mental Health, the Illinois State Board of Education and the Illinois Department of Children and Family Services.

The Interagency Management Team (IMT) provides guidance to the LANs. The purpose of this team is to gather stakeholders on a statewide level and offer information, support and technical assistance to the Local Area Networks of Care. The original membership of the IMT included a representative from each of the three lead agencies. No parent representation was on the original Interagency Management Team. The first parent participant began attendance in 1996 through the Illinois Federation of Families. Since that time, the membership of the IMT has grown to include many members on a local level as well as on a state level. Representation from the Illinois State Board of Education Behavioral Disorder Network comes from each of the four regions of the Illinois State Board of Education. The Community Residential Services Authority regularly attends, as well as special groups from time to time. The Interagency Management Team meets monthly. Each of Illinois' four regions (North, South, Central and Chicago Metro) takes turns hosting the meeting. This gives stakeholders the opportunity to discuss the innovative services each area of the state provides as well as sensitizing members to each region's unique needs.

The structure of LANs was developed following Child and Adolescent Service System Program (CASSP) principles and the system of care developed through the Alaska Youth Initiative that incorporated plans for all of the children involved. Guidelines and principles for the LAN movement were developed and each LAN was encouraged to also develop their Network of Care to reflect the needs and strengths of their individual communities.

Originally, the guiding principles for development of a C&A LAN included:

1. The system of care will be

firmly grounded in a philosophy of services which is child-centered, family-focused and community-based.

2. The role of parents should be that of active participants who are involved in service system planning, service provision and evaluation.

3. Participation in a C&A LAN planning process will be open and accessible to families, child and family advocates, and broad-based child-serving providers.

4. Each LAN will assure adequate representation of parents and children with emotional disorders, and members of culturally diverse racial and ethnic groups who are representative of the LAN population, in planning and implementation activities.

The rationale behind a unified service system was:

1. To clarify which agencies within a geographic area will assume responsibility for assessment, triage, and comprehensive treatment of children and adolescents in DMHDD's priority populations.

2. To eliminate gaps in service provision so that an array of core mental health services are available and accessible for the most disturbed and highest risk child and adolescent clients in the most effective and least costly settings.

3. To improve communication with parents of children with emotional disturbances, to facilitate access to appropriate services, and to improve the flow of information within the child/family provider community serving the same client or population.

4. To assure that transfer of individuals between service providers is made with the least disruption of services to the client.

5. To assure that conflicts between or among providers, consumers, or advocates within the service system are mediated by formal and informal mechanisms.

FOUR YEARS LATER

These guiding principles hold true today. Over the past four years, no new guidelines for formation of the C&A LANs have been written. Guidelines to clarify the allotment of flex funds and the reporting of those funds have been added. Over the past four years, there have been many successes and challenges in the development of the Local Area Networks of Care. The largest challenges involve:

1. The use of flex funds and the accountability of those funds;
2. The involvement of parents as decision makers in the Local Area Networks of Care; and
3. Interagency collaboration and accountability for interagency decisions.

In an effort to meet these challenges, several steps have been taken:

(1) The Interagency Management Team has developed guidelines that tie the expense of flex funds to the service plan developed by the child and adolescent team;

(2) The Illinois Department of Children and Family Services has entered into an agreement with the Illinois Federation of Families to recruit and train foster parents to represent the parent movement at local area networks of care;

(3) The Interagency Management Team Evaluation Group has been formed and is monitoring the evaluation that is being done across the state to track local and state level activities;

(4) Each LAN has been asked to appoint a lead agency for their area. This lead agency will carry the liability insurance necessary to cover facilitators who are autonomous and allows for parents to serve in different capacities;

(5) There is ongoing, unified wraparound training throughout the state. With each LAN participating, there will be a common definition of wraparound and will allow for a consensus on the service delivery system;

(6) Each LAN is being asked to expand the number of stakeholders at the table. The example of the Interagency Management Team and the

PACER CENTER NEWS

The Parent Advocacy Coalition for Education Rights (PACER Center) has been awarded a $1.2 million per year grant from the U.S. Department of Education for the next five years to establish the Technical Assistance Alliance for Parent Centers (The Alliance). The Alliance will provide parent centers with technical assistance, disseminate information, encourage collaboration between parent centers, help to develop Internet access to the parent centers, and will work towards systems change and school reform. The Alliance will also collaborate with national clearinghouses, regional resource centers and other education-related projects to identify approaches for effectively working with parents and educators and to distribute this information to parent centers.

The Alliance will operate through four regional centers. These centers are: Northeast Regional Center (Parent Information Center, Concord, NH), Midwest Regional Center (Ohio Coalition for the Education of Children with Disabilities, Marion, OH), South Regional Center (Partners Resource Network, Inc., Beaumont, Texas), and West Regional Center (Matrix Parent Network and Resource Center, San Rafael, Calif.). The Alliance can be reached on the Internet at www.taalliance.org or by calling their toll free number, (888) 248-0822.

PACER Center is a coalition of 20 disability organizations with the goal of providing training, advocacy, and information for families of children and young adults with disabilities. The Center also serves as a resource for professionals in the fields of education, health, and human services. On September 17, the PACER Center will be celebrating its twentieth anniversary! PACER Center can be reached on the Internet at www.pacer.org or by calling their toll free number, (800) 53-PACER.

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ongoing training will help encourage this participation and help expand the level of community commitment to the LAN movement.

Parents' roles have changed in many ways since the beginning of the LAN movement. Parents are more involved in the development of the service delivery plan and many parents have taken lead roles in their Local Area Networks of Care. In one LAN, a parent sits as a co-convener.

In six LANs, family resource centers have been formed. These centers allow families to offer parent-to-parent support and information. Many of the resource centers provide facilitators, mentors and resource developers to the child and adolescent teams. The formation of these resource centers has helped enhance the parent/professional partnership and built trust between collaborators.

As the Local Area Networks of Care approach their fifth year of existence, we hope that the networks will continue to grow and reach out to include additional community members. Parents continue to play important roles in the identification and recruitment of necessary stakeholders and in the expansion of the Local Area Networks of Care. The forward movement of the LAN is the product of a deep commitment from our Illinois Department of Children and Family Services, the Illinois State Board of Education, the Department of Human Services, national leaders like Lucille Eber, and parents who believe this service delivery system continues to provide better outcomes for children and their families.

KAREN GORA, *Director of Illinois Federation of Families Parent of two children with serious emotional challenges. Illinois Federation of Families has been the parent organization present at all of the 62 local area networks of care and member to the interagency management team as well as a partner in the community wraparound initiative (one of thirty-one hub sites across the country involved in demonstration grants from the Center for Mental Health Services). (630) 858-1649.*

PARTNERS AT THE POLICY TABLE

The story of the Massachusetts family movement officially began in 1989 when the Department of Mental Health (DMH), the state mental health authority, funded a staff position for the Parent Professional Advocacy League (PAL). The goal of this effort was to provide parent-to-parent information and referral, organize parent support groups on a peer-based model, and develop the parent perspective as a key element of public policy discussions. In 1992, DMH used federal block grant funds to create parent advocate positions in two of seven DMH Areas, and later expanded to all the DMH Areas.

Today, within the DMH system, parents are represented on advisory boards internal and external to the Department. They are involved in assessments of the existing systems of care, and in the reconfiguration of the service array and development of new program designs.

Parents are represented on all proposal review committees related to children's mental health service procurement. The role of families in public policy discussions, however, represents the most significant innovation in the state's family involvement, particularly as it relates to managed care.

At the direct service level, parents have served as coaches to other parents. They have proved effective in helping families participate effectively in the service planning process. Parent advocates have also linked families to other community resources for children with mental health problems and modeled advocacy skills.

The latest evolution of the parent role is in its introduction to the interagency world of child welfare and juvenile justice. DMH and the Department of Social Services (DSS) are expanding statewide a pilot project that is targeted to youngsters with serious emotional disorders who are on the brink of out-of-home placement yet who fall outside the purview of either the child welfare or mental health agencies. A jointly funded assessment and crisis stabilization service has the authority -post assessment - to assign the child and family to a specific state agency. This program incorporates parents as family partners from the first day of the assessment.

Parents, along with DMH and DSS, participate in the hiring of the project director, are members of the statewide Steering Committee and serve on all local advisory committees. Family partners are linked with incoming families to offer support and guidance, which can be maintained long after the assessment ends. Feedback from families has all but cemented this role as a core part of the program model. At a meeting of DMH and DSS field leadership in October 1997, which was convened by the Commissioners of both agencies, staff were introduced to the service model and heard from their peers about its successes in the pilot site. The parent presentation at the meeting represented a first in child welfare circles. Linda Carlisle, Commissioner of DSS, in a post-meeting thank-you to the organizers and presenters, wrote: "I finally understand what the family partners do—we at DSS can learn a lot from this model."

At the Department of Youth Services (DYS), the Massachusetts juvenile justice agency, a beginning step is being taken to offer parent support activities to parents of youngsters in DYS custody who have mental health problems. The lengthy development process suggests some trepidation; however, planning is proceeding. PAL has been the motivational organizing entity and continuing advocate for this new direction.

A new and promising direction for interagency focus is in the develop-

ment of outcomes for children who receive services from multiple systems. DMH has convened a process with DSS, Medicaid, Massachusetts Behavioral Health Partnership (the Medicaid managed care entity), provider groups and trade associations, and families to decide on a standardized tool that will be used by all public purchasers. There is the potential for parents to assume a unique leadership role in crafting family relevant outcomes.

In my view the key contributions to the growth and significance of the family role in the mental health delivery system for children in Massachusetts are the following.

1. The commitment of top leadership. A sense of vision of the potential and the possible; willingness to simply say "this shall be," to those less able to believe in the vision. A "feel it in my bones" belief in the rightness of the direction. Without that, it can't work because it's too hard and too frustrating. Our experience shows that, over time, the case is made and the impact is clear. Top level commitment must then translate into middle management responsibility for providing the needed technical assistance, troubleshooting, and communication up and down the state mental health authority, as well as the children's mental health community.

2. Money. It takes one or more individuals on a payroll to assure the needed focused and persistent effort. It takes travel, occasional hotel costs, phones, a computer, copying availability, supplies, etc., etc. DMH now spends $800,000 on activities related to supporting and working with parents as partners in direct services and public policy.

3. A willingness to capitalize on every opportunity to include the parent voice at every relevant table. Initially PAL needed DMH to create the seat at the Medicaid managed care table. Once set, with all parties acclimated, DMH could retreat. Now PAL's extraordinary experience and solid reputation as an important contributor will assure its continuation in the role. DMH is there if needed. We continue to debrief, debug, and to design. Currently, DMH is bringing the parents to the interagency table. We envision the same process will unfold there as it has within DMH.

Our state has traveled far in the last eight years and yet it is clear we are only beginning. The changing health care environment suggests more and different players at the tables of the future. This year the questions posed are:

How do we think about influencing the HMOs as they become more central to our populations care? How do we respond to providers whose compensation is increasingly restricted to face-to-face interventions? Who pays for the value added time of including parents, at times convenient to them, at the policy table? How do we interface with the other family initiatives and with health care initiatives? What is the best structure for continuing family advocacy?

Eight years ago, and each ensuing year, we have posed a different set of questions. Given the sensitization of policymakers and caregivers that has occurred over time, we have moved from the point of trying to convince policymakers to invite parents to the discussion table to the point of including parents in all substantive planning committees, task forces, and review bodies. The success of this venture has been nothing short of remarkable.

As family advocacy has grown in sophistication and effectiveness, the challenges that family advocates now take on in Massachusetts are at the forefront of children's mental health policy. For professionals and families alike, the process has been a step-by-step chipping away at perceived opinions and beliefs about family involvement.

JOAN MIKULA *has been the Assistant Commissioner for Child/Adolescent Services at the Massachusetts Department of Mental Health since 1985. She came to the public sector with experience in education, juvenile justice and child welfare and views herself as a professional family advocate.* (617) 727-5600 x543

PARENT LEADERSHIP TRAINING INSTITUTE

The Parent Leadership Training Institute

The Parent Leadership Training Institute (PLTI) works to provide the skills necessary for parents to become advocates for their children. Through a 20-week course and a practicum in a community setting, parents are taught the basics of democracy, their rights, and the skills necessary to work with media and all levels of government in order to have an effect on public policy. The PLTI training program seeks to develop in parents "the capacity to interact within civic society with purpose and positive outcomes for children." The PLTI is a multi-generation strategy, with each class of graduates serving as mentors for the following class.

Participants in PLTI classes vary in age from teen parents to grandparents, and come from a wide range of backgrounds, with some being adoptive parents, single parents or step parents. The program is parent-based, and applications are only accepted from individual parents and not from institutions. Child care and other family supports are provided to class participants. The training is not specific to any one issue, but instead seeks to train parents to advocate for any issue of concern to them and to their children. For more information on the PLTI, please contact: The Commission on Children, 18-20 Trinity Street, Hartford, CT 06106 or call (860) 240-0290.

RHODE ISLAND'S EFFORTS TO PROMOTE FAMILY MEMBER PARTICIPATION IN POLICYMAKING

Though Rhode Island is often referred to as the smallest state in the nation, it has strong values, and an enormous commitment to the well being of children and families. Historically, policymakers in the General Assembly have consistently held a proactive view toward developing and implementing laws that ensure the quality of life for its citizens. In 1980, the Department of Children, Youth and Families (DCYF) was created by the state legislature, effectively merging children's programs previously administered by four different state departments, in response to public demand that there be one agency solely dedicated to the protection and support of the needs of children and families. Since its inception, the Department has evolved and transformed to meet the ever-changing needs of an increasingly complex social environment.

In 1986, the Division of Children's Mental Health was created to respond to the mental health needs of children, and new programs and services were developed. These mental health services are available to children and their families in Rhode Island, regardless of their status with DCYF. Today, the Department of Children, Youth and Families in Rhode Island is a unified state agency that has responsibility for child welfare, children's mental health and juvenile justice services.

CHILDREN'S MENTAL HEALTH SERVICE SYSTEM

The Department's responsibility regarding children's mental health is to design, implement and monitor a statewide system of care for children and youth requiring mental health services. Our responsibility also is to plan a diversified and comprehensive network of programs and services to meet the needs of children with serious mental, emotional or behavioral disorders; to provide the overall management and supervision of the state program for children with mental health needs; to promote the development of programs for preventing and controlling emotional or behavioral disorders in children; and to coordinate the efforts of several state departments and agencies to meet the needs of children requiring mental health services. Children who are placed in the custody of the Department due to abuse, neglect, dependency or delinquency, as well as children who remain in the custody of their parents or legal guardians, are eligible for services.

The present system of children's mental health services is organized on a community-based level to provide 24-hour emergency services and screening for inpatient psychiatric hospitalization; but, importantly, there is a community-based program component that works to prevent out-of-home placement. Our Children's Intensive Services (CIS) component is a six-month program which provides a vast array of traditional and non-traditional therapeutic services for the child(ren) and family. The CIS program, emergency services, and screening for hospitalization, are delivered through contracted services with eight local community mental health centers located throughout the state. The Department of Children, Youth and Families' Division of Children's Mental Health and Education operate from a centralized office in Providence, the state's capital.

In addition, there are eight Local Coordinating Councils (LCCs), contracted within the community mental health catchment areas. The LCC is a network of providers, families, advocates and community organizations that work together to develop a coordinated system of care for children and youth with serious challenging behaviors, with the goal of preventing out-of-home and out-of-community placements. These LCCs evolved from the Child and Adolescent Service System Program (CASSP), which was begun in Rhode Island in 1991, as part of the Department's move toward community-based partnerships with families and providers.

The guiding principles of the LCCs include integrated services across providers; child-centered, strength-based services; family-driven service planning; culturally competent services; flexible services close to home; integration of natural community supports; and community ownership. The LCCs meet monthly, and are responsible for assessing their families' service needs, identifying system barriers that impede effective service delivery, reaching out to families and local community organizations, advocating for system changes, and managing the case review. The LCCs do not provide direct clinical services. Each LCC has at least one multi-agency Case Review Team that reviews cases to assist the family in identifying and coordinating needed services within the community's system of care.

Through advocacy and guidance, the LCCs' Family Service Coordinators assist the family and/or the family's case manager in linking to the identified services and navigating the system of care. Services available through the LCC case review process include therapeutic recreation, respite, in-home behavior therapy and parent training, day treatment, therapeutic foster care and wraparound services (non-traditional supports for the child/youth and family). Services are provided by community agencies, many of whom are participants in the LCCS.

FAMILY INVOLVEMENT

The involvement of family members in making decisions about appropriate services for their children and their own home environment is paramount to the activities of our Department, and the work within the Local Coordinating Councils. We recognize

that parents do have the best knowledge of their children and that they are the primary caregivers, often providing the day-to-day emotional and environmental support for their children. Without their guidance and knowledge, the services may not be the most appropriate to meet the individualized and unique needs of each child and family.

In 1994, Rhode Island received a federal $15.8-million Services Initiative Grant from the Center for Mental Health Services, largely as a result of the degree of significance our state places on family inclusion in determining appropriate services, and in creating a comfortable environment of respect for parents as meaningful partners. The Services Initiative Grant, which we call **Project REACH Rhode Island**, authorizes funding to improve service capacity, and to research the development and implementation of program needs that were defined with family and provider involvement in the grant application. These funds are targeted to plan and implement non-residential and community-based integrated services statewide. The five project goals are to:

- augment existing services;
- develop new services when indicated;
- monitor and evaluate the system of care;
- assure diverse participation; and
- strengthen the existing inter-agency framework.

Parents of children with serious emotional/behavioral challenges are strong advocates and have a tremendous ability to argue with passion and tenacity for the public policy strategy that they feel most reflects their needs. One primary example of this force of energy and commitment involves legislation that was enacted last year relating to proceedings within our Family Court under "commitment of voluntary placements." This legislative proposal was introduced to the General Assembly in February 1996 to clarify and correct an existing law that had created an untenable position for the Department of Children, Youth and Families to require that families relinquish custody of their children in order to receive necessary out-of-home placement services. Our Department was sensitive to the tension created by this practice, and was receptive to suggestions and recommendations from families to reexamine the existing statute for a more family-focused amendment to relieve the tension and allow parents to retain custody rights for their children, and still seek necessary treatment assistance through our Department.

A special task force was formed, and met on a monthly basis for a year, throughout most of 1995, developing the legislative amendment to be introduced as House Bill 8337 in the 1996 session of the General Assembly. This task force was comprised of parents, advocates, legislators, representatives from the Governor's Policy Office, a representative of the federal Regional Office of the Administration for Children and Families, representatives from our legal staff and Children's Mental Health and Education. The legislation was well received and enacted into law upon passage. The work involved in developing this legislative amendment demonstrates the value and quality of family involvement in making sure that public policy does not miss the goal, but truly represents the best interests of children and families.

CHILDREN'S MENTAL HEALTH ADVISORY COMMITTEE

The Children's Mental Health Advisory Committee (CMHAC) was established six years ago through development of the Local Coordinating Council networks in partnership with the Parent Support Network. It represents the local chairpersons of the LCCS, family service coordinators, parent advocates, and representatives of other provider agencies, as well as representatives from Children's Mental Health and Education. The CMHAC has two co-chairs, elected by the committee. One co-chair is a family member, and also director of the Parent Support Network; the other co-chair is a local agency representative. This committee serves to advise the Department of Children, Youth and Families on issues and concerns for services, in an effort to continuously improve the quality and capacity of services for children and families. The legislative amendment enacted last year is an example of the committee's work with the Department to effect change in public policy. The LCCs have also increased the number of case review teams, and enhanced service capacity within their communities, as a result of the Project REACH funds, expanding awareness, appreciation for service coordination and family involvement.

INTEGRATED MANAGED SYSTEM OF CARE

Rhode Island's Department of Children, Youth and Families is concerned, as are other states, about the implications of managed care on the service needs for families with children who have serious emotional and/or behavioral challenges. Our Department is seeking to develop an integrated managed system of care, as opposed to a managed care system. We have the unique circumstance of being a unified state agency, and having the ability to develop a continuum of service needs that spans our population which includes families who do not have a legal status with our Department, to families who are receiving services through our child welfare programs, and on through to children and youth who are involved in our juvenile correction system.

Throughout much of last year, our Department worked on developing a design for an integrated managed system of care with a small committee comprised of representatives from the Parent Support Network, the Council of Community Mental Health Centers, the Children's Policy Coalition, the Consortium of Residential Providers, a representative chair of the LCCs, a community advocate, a representative of special education, and representatives within DCYF's Financial Management, and Children's Mental Health and Education. This

committee identified the values and principles for a system of care, which envisioned further development of community and family partnerships for shared responsibility in determining the levels of care and the utilization of a comprehensive array of services.

As a result of the work in this committee, and particularly the family involvement, the Department issued a Request for Letters of Interest in September 1996 to solicit community responses, which would further advise DCYF as to the communities' capacity, creativity and commitment to form a collaboration that would be able to develop a system of care to meet the standards represented in the values and principles. The responses to the Letters of Interest have been an important barometer in helping the Department to work more diligently on the development of a Request for Proposals, which will result in a practical system design representative of the needs of the populations receiving services through our Department.

MAINTAINING THE INITIATIVE

Funding for children's mental health services comes from multiple sources, including state agencies, Medicaid, private insurers, and federal grant dollars. A question which continues to be reviewed and discussed at all levels is what will happen to the enhanced community-based services funded by federal grant dollars once the grant funds have been exhausted, which is currently projected to be February 2000.

The Department of Children, Youth and Families, with family involvement, is presently beginning to work in a dynamic partnership with the Department of Human Services (DHS), which has sole authority for administering the state Medicaid plan. Our intentions are to review those services being provided which have proven to be effective for the children and families, and then work jointly with DHS to maximize our purchasing ability, perhaps blend funds, in order to continue, and enhance, an integrated service network for children and families in Rhode Island. Our goal is to provide services that are meaningful to children and families, and finally arrive at our dream of a seamless system of care—so families do not need to be so confused and frustrated about where to receive services.

KATHRYN B. NICODEMUS, LICSW, *Chief, Children's Mental Health and Education, Rhode Island Department of Children, Youth and Families, (401) 457-4514.*

FAMILY MEMBER INVOLVEMENT IN POLICYMAKING IN VERMONT

In Vermont we ask an awful lot of some of our family members who have children with emotional/behavioral disabilities. We ask them to overcome potentially consuming emotions such as sorrow, grief, frustration, and rage. We ask them to work with us even when they are facing potential exhaustion, intermittent crises, and all the stresses of a regular life in this culture. Some people might say we ask too much. Perhaps we do, but we have no real choice. Our system of care is far from perfect, and it will never develop sufficiently without their help.

Our system of care involves many components of necessary development. In this article we will glance briefly at four basic components: legislative advocacy, service planning and evaluation, case reviews and training, and government councils.

LEGISLATIVE ADVOCACY

The basis for any enduring system of care lies in supportive laws and their regulations. During the past

three years Vermont has passed several major legislative initiatives that have set a new national standard in the fields of health care and behavioral health care reform. Family members have played a key role in this political process.

This past June, for example, after a challenging but highly successful legislative battle, Vermont's Governor, Howard Dean, signed into law the nation's most comprehensive and expansive mental health and substance abuse parity bill. The Vermont law mandates the end of discriminatory practices in the construction of health care benefits in the commercial market; it creates real parity between the treatment of the brain and the body.

With less fanfare three years ago, Vermont enacted a major piece of health care reform legislation when it approved the Vermont Mental Health Utilization Review law. This bill, one of the most aggressive in the country, establishes a clear regulatory mandate for all mental health managed care companies doing business in the state while also creating a strong consumer protection grievance process.

"If we utilized a secret weapon in Vermont," said Ken Libertoff, Director of the Vermont Association for Mental Health and architect of these two legislative initiatives, "it is the realization that parents, family members, consumers, and concerned citizens make the best and most compelling advocates at the State House."

The Vermont Parity bill came under consideration in both the House and then the Senate this past winter and spring. Groups such as the Vermont Alliance for the Mentally Ill, the

Vermont Federation of Families for Children's Mental Health, and Vermont Psychiatric Survivors were highly active participants in two public hearings as well as in testimony before key committees. Reflecting on the winning battle, Representative Paul Poirier, chairperson of the House Health and Welfare Committee, stated that this testimony was a crucial factor in moving the bill to passage.

The Vermont Mental Health Utilization Review bill was in serious trouble three years ago until the mother of a severely troubled teenage daughter took the witness stand. With clarity of detail and the power of emotion, this parent, in one hour of riveting testimony based on her family's experiences, refuted and rejected several days of arguments about theory and probabilities by managed care companies against the regulatory bill. The bill not only moved out of the committee, but it made its way to the Governor's desk for final approval and was signed into law.

SERVICE PLANNING AND EVALUATION

Once we have the authority and funding to improve the system of care, we must plan services and supports to implement such improvements, and then evaluate the results to assure we are moving in the right direction. One recent example of family involvement in such a process is our Families First initiative.

Since its beginnings in 1993, the Families First initiative has involved parents as full partners with professionals in each phase of its process, from initial service planning and implementation to evaluation, feedback, and services modification. This initiative was designed to strengthen and preserve families of children experiencing serious emotional and behavioral problems. It did so by providing access to mental health and other community-based services to families in crisis, in a child-centered, family-focused manner. Initially priority services were planned and implemented by local governance boards in each of the state's 12 regions. As participants of these regional boards, family members provided critical, practical insights about gaps and needs in the service system and helped devise family-friendly methods to fill them. In this same role, they also helped to develop desired outcomes and to select specific indicators to monitor progress toward them.

From the time children and families began receiving new services, the data collection phase of evaluation was put in place. Family members and other caregivers became the cornerstone of this process. The "data" originated with the words of each youth and parent, with the telling of their stories to an intake worker in a local agency. Courageously, 529 parents and caregivers and 302 youth have given time and thought to share their lives and their ideas to help improve the system. The importance of this is underscored by Howard Stevenson, "The lion's story will never be told if the hunter is the one who tells the story." Youth and parents have also assumed the role of columnist for the initiative's newsletter, offering insight about ways of navigating within the system of care.

To ensure a family-focused evaluation, we hired a parent as an interviewer on the state evaluation team. This parent had spent years learning to advocate for her own children within the service system. Not only did she provide a greater than 85% interview completion rate of caregivers who had no phones and lived in hard-to-find rural homes, but she also tirelessly kept us grounded in the family perspective. She has since moved on to create and become the Director of Family TIES, an organization which provides training, information, empowerment and support to families. Another parent has recently been hired as a member of the research team.

As more information was compiled about individual youth and their families over time, feedback of preliminary outcomes was provided specific to each region. A parent group was formed to examine the data and design a format in which to present this information to each family who participated in the evaluation. This group continues to contribute consultation to the team.

The ongoing presence and voice of family members in all aspects of Families First maintains the integrity of the communication cycle of learning from families about what they need and what helps in their lives, and returning this information to regions to modify services. As one parent affirmed, "For me, the main question will always be, 'Will this activity help my child?'"

CASE REVIEWS & TRAINING

While it is vital to plan services and evaluate the results in order to improve the future system for everyone, it is equally vital to pay attention to individual, real children and families while we are still struggling in our existing system.

Part of Vermont's system for youth with emotional/behavioral disabilities and their families was put in place in 1988 with the passage of Act 264. It created our system of care, a statewide network of Local Interagency Teams, one State Interagency Team, and a Governor-appointed Advisory Board. We have a Family Representative on each of our Local Interagency Teams and on our State Interagency Team. One-third of our Advisory Board consists of Family Representatives. All of them are paid for their time.

A basic purpose of the Local Interagency Teams is to assure that no child or adolescent with a severe emotional disturbance "falls through the cracks" while we are building our system of care. Any family member or service provider who feels that the needs of a specific child are not being met through the normal operation of the system has the right (assuming parental permission) to turn to the Local Interagency Team for technical assistance. Typically this involves advice on what types of services or supports might be helpful, or on how to find funding if a child is not eligible

through the usual channels. Occasionally the child's interagency treatment team may not be able to agree on a coordinated service plan. In such cases, the team may ask for help to work towards consensus.

In all of these situations, the point of view of the family is vital to success. We urge families to attend these meetings of their region's Local Interagency Team, but realize that it can be intimidating to walk into a room full of professionals knowing only one or two of them in advance. Therefore, we offer the opportunity to talk with the team's Family Representative before the meeting. This can be in person or by phone. We hope to explain the purpose of the meeting, give some guidelines about what the team can and cannot do, set up a feeling of safety within the meeting, and offer the element of support from another family member. And, if the family does not attend the meeting or if the child is without a family at the time, the Family Representative acts as the "family conscience" of the group, a voice reminding professionals that children are entitled to a caring family and adequate supports and services. It makes a difference to a sitting team of professionals to know that the push for action, especially action which challenges current system abilities, is coming from a team member who sees both sides: the limitations set by law, budgets, and public policy on the providers, and the exigencies of the child's and family's situation.

Walking into any major bureaucracy (e.g., education, mental health, child welfare, physical health) for the first time is overwhelming. Trying to get something specific out of it is even harder. Our children and families have to manage these tasks in several major bureaucracies at once. Our families have asked for several years for training in system organization, functioning, and advocacy to help get them on the same footing as the professionals who spend their life learning the in's and out's of their systems. We have been working to develop such a training curriculum with the Vermont Federation of Families, the Center for Community Change at Trinity College, and the University Affiliated Program at the University of Vermont. It is nearly completed and the Federation has already offered the existing components to numerous families in several regions around the state. Family members and professionals alike seem very pleased with the results.

GOVERNMENT ADVISORY COUNCILS

"Is there a polite way to do a revolution?" asks the button on my friend's book bag. We're trying.

Vermont over time has developed many government advisory councils and boards with family member involvement. But Vermont is small, and the energy of advocates is spread thin. We decided that families of children with different disabilities should not be pitted against one another to "fight over the bones" of insufficient resources in a state with a small economic base. The Vermont Council for Families of Children with Significant Disabilities was born from coalition one year ago. We are committed to working together for whatever each needs to succeed. We have also strengthened common ground between families and individuals with disabilities. These connections enabled us to attach parts of our Family Support bill to a popular bill for long-term care for individuals with disabilities, riding its coattails to victory and establishment of a state council.

This council's composition and duties reflect national legislation in PL 103-382, the Families of Children with Disabilities Support Act of 1994. The majority are family members of children with disabilities under the age of 18. Currently the position of chairperson, required to be a family member, is shared between two fathers: one a veteran of advocacy in family support, and one newer to the field. This mirrors the council's composition, which includes long-time advocates mentoring younger families, who bring the renewing energy needed to move forward. Other members of the council are decision-makers from relevant state departments, with particularly good attendance from mental health, developmental services, and special education.

Major issues on the council's plate include working to:

- restructure respite programs to increase coordination, flexibility, availability, and sufficiency
- ensure a plentiful supply of trained respite workers
- clarify issues of taxation and unemployment benefits for respite workers and families
- ensure a trained, family-centered service delivery system with multiple points of entry to the system, each point accessing the whole system
- create a single Medicaid pediatric waiver across disabilities
- require community-based organizations to include in contracts clear family-centered goals and outcomes upon which future funding will be based
- develop clear, consistent definitions across human services of: "administrative costs," "costs that are direct services to families," and "costs that are services to children with disabilities"
- increase opportunities for alternate dispute resolution procedures
- create a safety net for children losing benefits under the new federal welfare reform act, including increased funding for EPSDT (Early and Periodic Screening, Diagnosis, and Treatment) services
- recommend ways to ease transitions to adult life for people with disabilities
- increase state funding of special education
- promote public awareness of challenges faced by children with disabilities and their families

CONCLUSION

So in Vermont we may be guilty of asking an awful lot of some of our family members. Fortunately, they have a tremendous amount to give. In spite of everything life throws at our families, many of them find the energy, concern, compassion, and

hope to commit to helping others individually and to tackling system change. Their presence alone reminds all of us of the price of failure; some have children who have committed suicide or spent time in jail. Their presence also reminds us of the possibility of success; some have children who are attending high school or college, have found jobs, and are engaged in their community. But presence alone is inadequate. We need their wisdom gained from experience, their creative problem solving ability, and their passionate drive for improvement.

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From left: Nancy Pandina, Alice Maynard and Susan Yuan

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FAMILY-PROFESSIONAL RELATIONSHIPS: MOVING FORWARD TOGETHER

A summary of the National Peer Technical Assistance Network's 1998 publication

We are seeking a new way of thinking about the relationship between families and service providers at both the individual family and the policy level. This philosophy is one that emphasizes the interdependence of us all and the need to engage as allies in the struggle to improve the lives of our children. It is a philosophy that recognizes the importance of sharing power. Family members rarely share the same access to power as do providers or policy staff. This leads to feelings of fear, distrust, anger and competitiveness.

For a variety of reasons-historic, cultural, social, economic-our service systems have been constructed so that professionals are perceived as having power over family members along with their children as users of their services. Professionals have more access to such resources as political power, purchasing power, information, educational skills, and the benefits of social status. Family members often feel depleted of financial, emotional, political, and informational resources. Consequently, they experience very little control over their lives, or the lives of their children, when they seek help in the care and development of their children with serious behavioral, emotional, and cognitive difficulties.

POWER OVER	POWER WITH
Self Interest	Community Interest
Winning	Cooperation
Controlled Access to Valued Resources	Shared Access to Valued Resources
Hierarchical Thinking Structure	Non-Hierarchical Thinking Structure
Controlled Participation	Open Participation

Preparation for the empowerment process: Identifying competencies and developing skills. Barr, D. & Cochran, M. (1991).

The ideal situation in the relationship between families and professionals is one where no one group has power over the other. Power resides within the system, with both groups working together to enhance their effectiveness.

When professionals begin to recognize what family members already know-that families are critical participants in the ecosystem in which children grow-the challenge is reframed. It no longer makes sense to think about how to bring families into an arena to which they already belong. Once everyone fully recognizes and appreciates the membership they already have, the task becomes one of how to develop and maintain authentic connections between all members of the system. In a systems view—where all life is seen as connected—all members, groups, and organizations of a community are interdependent. "The success of the whole community depends on the success of its individual members, while the success of each member depends on the success of the community as a whole."[1]

SYSTEMS THEORY

In systemic or ecological thinking, networks are key. Power comes from anywhere in the system and is conceived of as influence of others. Connectedness and relationships among the parts of a system are vital to its survival. The essential properties of a

system arise from interactions and relationships among the parts. Members of the system collaborate, cooperating to achieve their ends. There are no hierarchies of systems, just networks nesting within other networks in a web.

The basic principles, outlined by both Capra and Senge, for building sustainable systems include interdependence, the cyclical flow of resources, partnership, flexibility, diversity, and-as a consequence of all those-sustainability. These principles apply to our work of building sustainable systems of care for children, their families, and communities.

Interdependence. All members of a community are interconnected in a vast and intricate network of relationships from which they derive their essential properties. Therefore, they are mutually dependent on one another. The success of the whole community is dependent on the success of each member and the success of each member depends on the success of the whole. Nourishing the community means nourishing these relationships.

The Cyclical Flow of Resources via Feedback Loops. The effects of actions, decisions, and behaviors in a system are not linear cause-effect chains, but rather ripple out in ever widening circles in the community. Actions reinforce or counteract each other through patterns of change that recur again and again. There is a reciprocal flow of influence so that every influence is both cause and effect. Nothing occurs in only one direction. As a result, everyone shares responsibility for problems generated by a system.

Partnerships. Partnerships are the tendency to associate, establish links, and cooperate. They are essential for sustaining a system. Partnership arrangements ensure democracy and personal empowerment because each member of the community plays an important role. As partnerships evolve, each partner better understand the needs of the other. This results in both partners learning and changing. Cooperation and partnership replace competition and domination.

Flexibility. Because conditions are continually fluctuating, ecosystems survive by maintaining a readiness to adapt to changing conditions. Prolonged stress results from rigidity, or lack of flexibility, and can destroy the system. Flexibility also helps a system resolve inevitable conflicts.

Diversity. Diversity also helps a system to be resilient because it consists of members with overlapping functions and multiple approaches to problem solving. If a system is challenged, it will have numerous options for adapting, interpreting, and learning.

A community's strategies for involving families in operating and reforming systems of care will be more successful if they are based on these principles. Rather than seeing "families" and "professionals" as isolated singular parts who work independently of one another, we begin to see each as associated parts of a larger, integrated whole. Rather than in competition with each other for control of scarce resources, where if one side gains the other loses (be it power or access to resources), they are interdependent. The values of cooperation and partnership become central to survival of the common good.

CHANGING BUREAUCRACIES TO INVOLVE FAMILIES.

In their zeal to balance equity, quality, visibility, and accountability, traditional bureaucracies preclude flexibility, discretion, responsiveness, and effectiveness. The changes in bureaucracies that must take root to support a different way of working with families include:

- Administrative support to more actively involve family members;
- Programmatic and fiscal flexibility to develop comprehensive service plans based on family needs rather than services available;
- Training to shift from staff-dominated to family-centered approaches;
- Leeway to create opportunities, provide information and training, and offer concrete support services to families;
- Time for professionals to communicate with families and other professionals; and
- A system that makes them accountable, not in terms of units of services provided or individual activities undertaken, but rather by outcomes, by how skillfully they have engaged others in developing and implementing successful solutions.[2]

CONTINUUM OF FAMILY-PROFESSIONAL RELATIONSHIPS

There have been dramatic changes in the past thirteen years in the overall practice of children's mental health services. The most significant changes are evident in the services with individual families and with systems' level policy development. Planning has evolved from an expert driven, professional-centered approach to family-centered, team-supported infrastructures. These infrastructures develop and support interdependent relationships and interlocking services.

States and communities are, however, each at their own point of development in this evolution. Some have achieved far more progress than others have. We have tried to portray the stages of development in the form of a continuum. As they begin to consider strategies for moving further along, readers can use the continuum to determine where they are in their own development.

The stages are not discrete. A particular location may be further along in some aspects of this work than they are in others, but the process reflects progress as one moves from one stage to the next. Each state involves a stronger commitment to thinking and action. As a result, the evolving family-centered approach has a solid foundation as it moves through the development process.(Figure 2)

Professional-Centered. The agency works only with the child. Staff write treatment plans based on office interviews. Usually a single agency, or an agency operating alone, provides services to meet identified deficits. Usually the involvement of another agency includes formal re-

quests for records or a request to attend a meeting. Plans are never developed between agencies. The family may end up with three different plans.

Parents are simply not included in planning, delivering interventions, or evaluating their effectiveness. Parents are not asked what they need to help care for their child. They are rarely seen as a resource, and never as the primary agent of twenty-four hour care. Providers at this level view the family as part of the problem, if not the very cause of it. Juvenile justice and child welfare programs are frequent examples of this level of practice.

Providers make the decisions, know the "right" answers, and determine treatment. They work primarily from charts and other documents transferred from provider to provider. Providers frequently become frustrated and ineffective, perceiving family caregivers as unwilling and/or unable to do what they are told. They perceive the family caregivers as persons who won't get it right, won't follow through, and won't be consistent.

Family involvement in service and policy planning at this level is very rare. If there is any involvement, it doesn't go well. Providers experience families as fickle, non-compliant, non-committed, uninformed, angry, hostile, often aggressive, definitely resistant. Providers who attempt to plan with families who have been served at this level of practice find themselves defending the involvement to their colleagues, who say "Why do this?" Frustrated by the expense of providing childcare, transportation, lodging, up-front stipends to caregivers who appear ungrateful, they frequently decide that costs outweigh any long-term benefit to the agency or to the planning process.

Family-Focused. Providers recruit family members as helpers and allies in the child's treatment. The provider knows best, determines the plan of care, and shares it with the family members.

Once the family requests help at this level, providers meet with them to scrutinize their need for services. When the need for help involves more than one agency, many professionals become involved. This creates a situation where very personal problems are examined and shared across agencies. Involvement in the treatment process changes the family's role in the community. They see themselves and their providers see them as needing help, wanting advice, direction, and guidance for the child. By accepting help, family caregivers come to see themselves as people who need to be helped, can expect to be judged as good or bad, and need teaching and advice.[3]

What they receive, however, rarely matches their defined needs. This is especially true when their racial, gender, cultural, or socio-economic background is different from the provider community. Families get discouraged and angry because the provider recommendations don't really work; family members can't make them work. Yet, to get services—even services that they may not even see as very helpful—they must follow certain rules and wear the demeanor of a person needing help, of a person being helped. They learn to act dependent and passive with their caregivers.

Families in this situation feel they are under the scrutiny of providers who are searching for their deficits. They feel they are being placed in the same status as the child who needs help. They learn to accept that they themselves should seek therapy or enroll in parenting classes.[4] They begin to accept the judgments of the providers who assess how well the family follows the rules set out for them-if they meet appointments, if they follow the reinforcement schedule established by the therapist, or if they make the child complete the homework assigned by the teacher. These judgments are passed from provider to provider and are based on the perceptions, values, and standards of people who are strangers to the family's own values, culture, and beliefs.

At planning meetings, the family's experience, as well as the experience of most providers, is informal. It is

PROFESSIONAL–CENTERED	FAMILY–FOCUSED	FAMILY–ALLIED	FAMILY–CENTERED	TEAM–CENTERED
• Adversarial professional-parental relationship • Professional is the expert • Parent is the problem	• Families are helpers and allies • Caregiver is "one-down" • Professional is the expert	• Families are customer • Family caregiver is an equal • Family and professional work collaboratively to address mutually agreed upon goals	• Professionals are "one down" to families • Parents know best • Professionals role is to support families to help their child	• Wrap-around model • Team makes decisions • Team includes family, provider, child and others

Figure 2. Adapted from Table One: Children and Youth–The Continuum of Services in the National Peer Technical Assistance Network's 1998 publication

limited to "input." Families may experience opportunities to learn and to attend meetings, but they get frustrated and discouraged by too much or not enough information, by complex and bureaucratic mazes. They find they cannot attend enough meetings to be effective. Work and child commitments prohibit their real involvement. Furthermore, the families who attend such meetings are frequently not representative of the customer group-the actual service client whose issues are being considered. There has been no formalized process for selecting or recruiting families. The families represent no voice other than their own at the meeting. They are not accountable to any larger group of families for what they say.

Family-Allied. In this situation, providers meet with family members and invite them to join the service planning process as equals. They are to become partners in determining what services their child will receive. Providers and family members make decisions together. Meetings go on forever. Collaboration is the priority. Providers from different agencies inform families separately about what is available and what is not, one agency at a time.

Providers support what the family wants, what family caregivers say they need. Yet, the family frequently doesn't have enough information about services or enough contact with other families to know what to ask for. Since they don't know what to ask for, families say that they don't need anything.

Providers listen and search for services to match family needs. The provider operates in the "I have it. I know more. I'll get it for you" mode. The family operates from the "I need whatever you tell me I need" mode. Providers know what is best. When providers and caregivers figure out what the need is-possibly with a parent support consultant who is experienced with the service array—the relationship becomes more equal. Connecting with other parents who have secured services, who know the score, who can make suggestions and give advice from similar perspectives, encourages providers to focus on concerns and priorities of the whole family and encourages the family to request help rather than assume helplessness. Listening to family members' concerns, empathizing, and sharing common experiences, facilitates the family's ability to express their preferences. This assists them to best meet the needs of their child and family. Families want professionals to be sensitive, non-judgmental, and accept their diversity.

When providers are very good, the family grows to need services, expect services, and eventually demand services. Entitlement issues develop. Families look to these providers for interventions, for crisis help, for emotional support, and friendship. The family moves from independence to dependence to keep the relationships going. At this level, providing emotional support and maintaining professional distance is a challenge to many providers. Their training programs and service supervisors caution them against becoming friends with their clients and advise them to maintain a professional distance from those with whom they are working.[5]

At the systems level, everyone knows each other. Nice, behaved, respectful families are welcomed as stakeholders to provide input on committees. Demanding, aggressive requests for services for specific children, high expectations for service delivery, and specific outcome monitoring are banished by the culture of the alliances between specific providers. They also don't exist between agencies and even between individual families and their providers. Planners invite only families who are satisfied. Rarely are the customers of the specific services addressed. Even more rarely are they representative of the minority demographics of the population actually served.

Family-Centered. With family-centered practice, families know and want more. They ask, demand services, and engage their strengths. The Beach Center on Families and Disability describes practice at this level as discrete from traditional medical models where the role of the health care professional is to look at the situation and tell the family what to do for the child. Key components of family-centered practice include:

- focusing on whole families as the unit of attention;
- organizing assistance in accord with the family's strengths;
- normalizing and recognizing the typicalness of situations rather than emphasizing deficits; and
- structuring service delivery to ensure accessibility, minimal disruption of family integrity and routine.[6]

Team-Centered. Families select from existing service systems once they have information about specific services and what outcomes they can expect from those services. Their providers listen and attend to needs as the family identifies them. Providers offer information, services and the benefit of their professional training and experience. But it is the family who drives the plan and makes decisions about what is and is not working. Providers may become very frustrated in this role, as it threatens their professional training. The one-down relationship between provider and family devolves years of professional training and experience with many youth.

In addition to their service providers, the family caregivers may also access their own independent network for information and consultation. State and national family organizations serve to connect the family with other families with similar needs and offer them information and support through training in advocacy skills and in representing their needs to state and national decisionmakers.

At the service planning process, selected families may be loosely connected to other families but will be outnumbered by the provider community in number and background information. Providers, particularly at the state agency level, frequently recognize the state family organization and use it to recruit family participation in planning and in legislative advocacy.

Continued page 28

1998 BUILDING ON FAMILY STRENGTHS CONFERENCE HELD IN PORTLAND

The Research and Training Center on Family Support and Children's Mental Health hosted its annual conference on research and services in support of children and their families, April 19-21, 1998, in Portland. Participants from more than 35 states, three provinces of Canada and the several tribal nations attended.

Keynoter Robert A Naseef spoke on the topic: *Special Children, Challenged Parents, Helping Professionals: Building Links that Endure*. Naseef began his presentation by asking persons from the audience to share their responses to photographs of himself and his son, Tariq, who has autism. Family members, advocates, researchers and providers responded with stirring accounts of their own reactions.

Research and Training Center Director Barbara Friesen facilitated a panel of researchers who addressed how to measure "impact" on families when a child has a disability. The researchers were Ana Maria Brannan of MACRO International, Atlanta; Elizabeth M.Z. (Betsy) Farmer of Case Western Reserve University, Cleveland; and Diane Yatchmenoff, Portland State University, Oregon.

Friesen also brought together family members, researchers and others for a roundtable at which participants shared ideas, questions, and suggestions for improving family participation in research. She was joined in initiating the discussion by Krista Kutash, Mary McCormack, Elizabeth Scanlon, Ann Vander Stoep and Marilynn Williams.

Monday's luncheon was enlivened by practical and inspiring remarks from Ken Libertoff, Executive Director of the Vermont Association for Mental Health. Libertoff shared his experiences in leading the successful legislative effort in Vermont for mental health parity for health insurance.

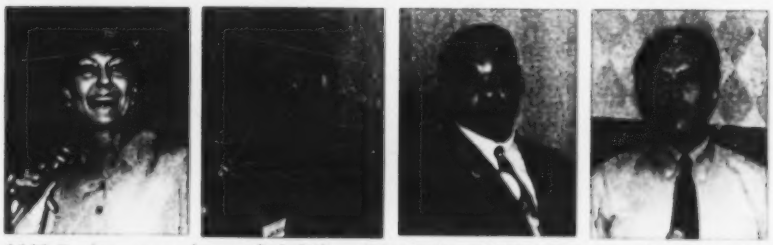
The final conference event was a panel of family members and media experts discussing "How to Get the Word Out About Family Strengths." The panel chair, Susan Dubuque, family member from Richmond, introduced family advocates Sandra Spencer, Liz Sweet and Sandra Campbell-Jackson who told their stories of successfully working with media in their local areas. They were joined by media experts Maya Blackmun of The Oregonian and John Faherty of KOIN-TV(6) in Portland, who described successful relationships between media professionals and advocates. Participants went home with manual on how to work effectively with media. Copies are available from the Research and Training Center by calling Denise Schmit at 503-725-4175.

Throughout the conference, 15 symposia, 39 paper sessions and 7 special sessions were held on topics ranging from computers and families to the language of family-centered services. Thirty poster presentations added to the mix of information and perspectives on family strengths.

Family members from 8 states and the Navajo Nation were recognized as honored guests of the conference, attending as representatives from their organizations.

Co-sponsors of the 1998 conference were the Federation of Families for Children's Mental Health, the National Institute on Disability and Rehabilitation Research, U.S. Department of Education; and the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

The 1999 Building on Family Strengths Conference will be held in Portland from June 3-5.



1998 Conference speakers included (from left) Barbara Huff, Keynote speaker Robert A. Naseef, Phillippe Cunningham and Ken Libertoff

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FAMILY-PROFESSIONAL RELATIONSHIPS CONTINUED

At planning levels, words like "family-driven" permeate service discussions. Power and control issues dominate. The family organization—which began with a mission of advocacy and family support—becomes a provider whose mission is to meet the unmet needs families identify. Families of different racial, cultural, and socio-economic status than their providers rarely experience this level of family-determined supports.

At this end of the continuum, services are developed to respond to family members' very specific needs. The family may ask to be their own case manager, with team members offering them the support they will need to effectively function in this capacity. The team calculates how this will be done. If needed, the team configures respite and attendant care and works with the family's schedules as well as those of the provider community.

The emphasis here is on the interdependence of services and the people who provide the services. People join the team and belong to the team because they offer help and support. Everyone identifies and shares resources. The family's strengths are imbedded in the teams. Team members' needs are considered as well as those of the family and the members are flexible enough to respond quickly. For example, the child's teacher says, "I am unable to provide this level of monitoring this month." Someone on the team-often a family member-asks, "What do you need?" Team members listen and devise supports to the teacher.

Supportive responses are quick, expected and delivered. Interdependence of the members is maintained. Diversity is honored. Team members set joint service goals and track outcomes. They hold each other's services accountable and share the responsibility to shore up informal resources with their formal infrastructures.

At this level, family members are encouraged and supported to belong to their state organization and to attend state and national meetings. They begin to organize, to develop their own information infrastructure, to receive information, and to access information before and after meetings. Professionals and families receive mutual support for good work. Families provide needed advocacy to move the system forward, to improve policy, and to secure new money for services. At this level, there are implicit and explicit understandings that families need providers for their services and value their expertise. Providers value families because they are the experts on if and how well services work.

We view team-centered family-professional relationships as the long-term goal towards which families and providers should strive in their mutual efforts to develop services at both the individual family and policymaking levels. Shared power increases respect and collegiality among team members and most importantly increases team members' abilities to identify, design and deliver appropriate services to children with serious mental, emotional or behavioral disorders and their families.

This summary was prepared by Marilyn McManus.

AVAILABILITY

This publication in its entirety will be available in September 1998. It is available through the following three organizations:

Federation of Families for Children's Mental Health
1021 Prince Street, 2nd Floor
Alexandria, VA 22314-2971
(703) 684-7710

National Resource Network for Children and Family Mental Health Services Washington Business Group on Health
777 North Capitol, NE
Washington, DC 20002
(202) 408-9320

National Technical Assistance Center for Children's Mental Health
Georgetown University Child Development Center
3301 M Street NW
Suite 401
Washington, DC 20007-3935
(202) 687-5000

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EAT PYE: YOUTH PARTICIPATION IN POLICYMAKING

EAT PYE (Entrepreneurial Action To Promote Youth Employment), of Janus Youth's Willamette Bridge Program's Business Partnerships for Youth, began with one volunteer, Gregory MacNaughton (now the program supervisor), teaching street youth how to cook in a local church kitchen. Street youth, MacNaughton comments "are usually given prepared food from shelters and, since they lack a kitchen, are never given the opportunity to learn to cook for themselves and be independent." As the program began to develop EAT PYE would donate a meal to a local shelter once a week. The one youth who regularly attended the program at its beginning decided that he only wanted to make pizza. Given the youth's enthusiasm for pizza McNaughton was easily swayed and this proved to be quite fortunate. Another local agency serving street youth in Portland, Oregon, Outside In, had been buying pizza on a weekly basis from an alternate source and overextending its budget. EAT PYE offered to provide pizzas for Outside In at half the price and thus a youth promoted venture was born!

EAT PYE has significantly grown beyond its basic inception. Since then, EAT PYE has become a licensed restaurant selling pizzas to other nonprofit agencies and the general public. Youth employees, Amy McCollum and Chrystal MacCoone both agree that the grant they received, in conjunction with Outside In, from Housing and Urban Development (HUD) is allowing them to expand their vision of reaching out to more street youth. This grant funds a youth/adult liaison team to promote public safety by providing employment opportunities for street youth. The funding came through HUD's Enterprise Committee, which provides grants to areas targeted as Enterprise Zones, one of which is downtown Portland, Oregon. EAT PYE receives approximately $20,000 from this grant, but fortunately EAT PYE now makes enough profit from pizza sales to fund two part-time youth positions, and operates a lunch-time pizza cart in front of the church that sells pizza by the slice.

Currently, there are two youth employees at EAT PYE. Amy McCollum, age 19, is the youth manager, and has been employed there for nine months. Chrystal MacCoone, age 17, is the head baker and has been employed at EAT PYE for six months. Another youth position is in the process of being filled. Chrystal and Amy both see lots of benefits from their involvement in EAT PYE. Neither one considers themselves a street youth anymore, although they did when they were hired. Amy now lives in an apartment, and Chrystal is in transitional housing. According to Chrystal, she has benefited by "getting job skills and learning how to just work with people", as well as learning to cook. Amy agreed and also emphasized her new teamwork skills. Amy additionally talked about the socialization involved in working in a church, where she has learned to watch her language and has formed relationships with church personnel. According to Greg, Amy is passing her new social skills on to other volunteer youth by example. Amy related how she had previously been quiet, but now was willing to talk to others about her opinions and experience with EAT PYE. Chrystal is now planning on getting her GED and going on to college.

Greg and Amy are in the process of learning how to share decision-making. Amy, as youth manager, trains new youth, and is in charge of product design. Greg, who for the last two years was unable to take a day off, now can leave Amy in charge while he takes time off. According to Greg, the amount of responsibility depends on the individual youth, and Amy is the first youth, so far, that he has felt comfortable trusting with this much responsibility. This responsibility extends to the community as well. Both Greg and Amy serve on the Public Safety Committee of the Downtown Retail Council. In this capacity, they are able to bring the story of street youth (as well as the story of their business), to local retailers. Amy and Chrystal are also being asked frequently about job openings by street youth. However, Chrystal has found that now that she is employed she is no longer accepted by the street youth as one of their own. Still, Amy and Chrystal serve as an important liaison to street youth wanting to become involved in EAT PYE or trying to change their lives.

Amy and Chrystal serve as an important liaison to street youth wanting to become involved in EAT PYE or trying to change their lives.

FUTURE VISION

Greg, Chrystal, and Amy all envision growth in the near future for EAT PYE. They would like to see more youth involved in the program, and more funding to support new youth positions. Also, they would like to see the EAT PYE model replicated in other communities. This could be easily accomplished since most churches have kitchens, and the program runs on a very small budget. Both Amy and Chrystal would like to have EAT PYE operate a store so that they can get more experience dealing with customers, as opposed to being a delivery business. The pizza cart is a start in this direction. Additionally, all three see the pizza cart as a way to reach out to the homeless, and plan to sell vouchers for free pizza slices that agencies can give to their clients and that the public can give to homeless people. Amy also intends to have a resource guide and pen available at the stand so that she can help people in need to find resources.

This article was prepared in collaboration with Amy McCollum, Chrystal MacCoone, and Gregory MacNaughton of EAT PYE Pizza and Focal Point *Editors Kelly Blankenship and Elizabeth Caplan.*

NOTES & COMMENTS

FAREWELL, MARILYN!

Marilyn McManus (right) with her family

With a mixture of regret and congratulations, we said good-bye to Marilyn McManus, who left the Research and Training Center in January, 1998. She was a part of our staff for 12 years. Marilyn also served as the excellent and eagle-eye editor for *Focal Point*. She is now working in the area of permanency planning in the child welfare system, which supports her long-term goal of developing greater expertise and capacity to serve in the field of adoption.

Marilyn first worked with the Research and Training Center as an M.S.W. student on the "Youth in Transition" project. Later, she was hired as the manager of the Resource Service which subsequently became the Center's National Clearinghouse.

An attorney as well as a social worker, Marilyn is especially interested in policy issues and she provided ongoing leadership around the issue of parents relinquishing custody to obtain services—both keeping a focus on national developments and working as part of a team to get the custody laws changed in Oregon. Most recently, Marilyn served as the Project Manager for a national study of polices that mandate family participation

We are grateful for all that Marilyn contributed and for her persistent advocacy to improve services for children with emotional disorders and their families.

Please join us in applauding Marilyn's many accomplishments; thanking her for her hard work on *Focal Point*; saying good-bye to a good friend; and in wishing her all the best in her new career.

TRAINING INSTITUTES ORLANDO, FLORIDA, JUNE 13-17, 1998

"Developing Local Systems of Care in a Managed Care Environment"

Several researchers from the Research and Training Center attended the 1998 Training Institutes organized by the Georgetown National Technical Assistance Center for Children's Mental Health. Since 1986, the Georgetown center has offered intensive Training Institutes to support communities as they develop systems of care for children and their families.

The impact of managed care on children's mental health services was one of the central themes of the 1998 Institutes. General sessions addressed emerging trends in managed care, as well as the compatibility of systems of care and managed care. Additionally, four young adults provided attendees of the Institutes with their own insights and perspectives on living with mental health challenges.

The next Training Institutes will be held in New Orleans, Louisiana, from June 9 to June 13, 2000.

CHANGES IN SPECIAL EDUCATION LAW

In 1997, several changes were made in the Individuals with Disabilities Education Act (IDEA). Some new requirements of the 1997 IDEA are:

- Individual Education Plans must include positive ways to address problems and include a students' strengths, not only their weaknesses.
- Students receiving special education must be taught using the same curriculum as other students, with only necessary adaptations.
- Parent permission must be given before any testing of their child, whereas before parent permission was only necessary prior to the first evaluation.
- Schools are required to include parents in all discussions about placement of their child.
- Transition planning must now be included in the IEP for all students age 14 and older. Previously, the age had been 16 years and older.
- The school system is now required to provide free, appropriate public education to students who have been suspended for more than 10 days or who have been expelled.

NEW PUBLICATION ON IDEA

The Bazelon Center for Mental Health Law recently published *A New IDEA: A Parent's Guide to the Changes in Special Education Law for Children with Disabilities.*

This publication provides a thorough explanation of IDEA 1997, parents' and students' rights as well as the process for disagreeing with the school's decisions. A resource list is also included in the publication. For more information on this publication, please contact the Bazelon Center at (202) 467-5730, 1101 15th Street NW, Suite, 1212, Washington, DC 20005. The Parent's Guide can also be accessed over the Internet at www.bazelon.org/idea.pdf. It is available in English and in Spanish.

STAFF TRANSITIONS

Farewell to: Bev Stephens who served two and half years as Family Resource Coordinator for the National Clearinghouse on Family Support and Children's Mental Health. Combining her own expertise as a family member with her counseling skills, she served countless families with a high degree of quality and compassion. We wish her sucess in her travel business, Blue Earth Exploration.

Anne Greenhoe, steadfast assistant for the Research and Training Center, will be missed. She left the Center to pursue graduate studies in theology.

Welcome: Janet Walker, Increasing Multicultural Parent Involvement Project, **Jennifer Simpson**, Promising Practices in Family Provider Collaboration, and **Susan Almquist**, support staff.

Congratulations: M.J. Longley! M.J. recently received her doctorate in Education after completing her dissertation *Promoting Partnerships with Families: A Descriptive Study of the Development, Implementation, and Evaluation of a Teacher Education Curriculum.*

PUBLICATIONS

❒ **AN INTRODUCTION TO CULTURAL COMPETENCE PRINCIPLES AND ELEMENTS: AN ANNOTATED BIBLIOGRAPHY.** 1995. *Describes articles & books that exemplify aspects of the CASSP cultural competence model.* $6.50.

❒ **BROTHERS & SISTERS OF CHILDREN WITH DISABILITIES: AN ANNOTATED BIBLIOGRAPHY.** 1990. $5.00.

❒ **BUILDING A CONCEPTUAL MODEL OF FAMILY RESPONSE TO A CHILD'S CHRONIC ILLNESS OR DISABILITY.** 1992. *Proposes comprehensive model of family caregiving based on literature review. Causal antecedents, mediating processes and adaptational outcomes of family coping considered.* $5.50.

❒ **NEW! BUILDING ON FAMILY STRENGTHS: RESEARCH, ADVOCACY, AND PARTNERSHIP IN SUPPORT OF CHILDREN AND THEIR FAMILIES. 1994 CONFERENCE PROCEEDINGS.** *Transcripts of plenaries including keynoter Lee Gutkind, Cleopatra Caldwell, Henry Levin and summaries of paper and panel presentations.* $8.00.

❒ **NEW! BUILDING ON FAMILY STRENGTHS: RESEARCH AND PROGRAMS IN SUPPORT OF CHILDREN AND THEIR FAMILIES. 1995 CONFERENCE PROCEEDINGS.** *Transcripts of plenaries including keynoter Karl Dennis, Peter Jensen, Velva Spriggs & Janice Hutchinson and summaries of paper and panel presentations.* $8.00.

❒ **CHANGING ROLES, CHANGING RELATIONSHIPS: PARENT-PROFESSIONAL COLLABORATION ON BEHALF OF CHILDREN WITH EMOTIONAL DISABILITIES.** 1989. *Examines barriers to collaboration, elements of successful collaboration, strategies for parents and professionals.* $4.50.

❒ **COLLABORATION BETWEEN PROFESSIONALS & FAMILIES OF CHILDREN WITH SERIOUS EMOTIONAL DISORDERS. ANNOTATED BIBLIOGRAPHY.** 1992. $6.00.

❒ **COLLABORATION IN INTERPROFESSIONAL PRACTICE AND TRAINING: AN ANNOTATED BIBLIOGRAPHY.** 1994. *Addresses interprofessional, interagency and family-professional collaboration. Includes methods of interprofessional collaboration, training for collaboration, and interprofessional program and training examples.* $7.00.

❒ **CULTURAL COMPETENCE SELF-ASSESSMENT QUESTIONNAIRE: A MANUAL FOR USERS.** 1995. *Instrument to assist child & family serving agencies assess cross-cultural strengths & weaknesses.* $8.00.

❒ **DEVELOPING AND MAINTAINING MUTUAL AID GROUPS FOR PARENTS & OTHER FAMILY MEMBERS: AN ANNOTATED BIBLIOGRAPHY.** 1990. $7.50.

❒ **FAMILIES AS ALLIES CONFERENCE PROCEEDINGS: PARENT-PROFESSIONAL COLLABORATION TOWARD IMPROVING SERVICES FOR SERIOUSLY EMOTIONALLY HANDICAPPED CHILDREN & THEIR FAMILIES.** 1986. *Delegates from thirteen western states.* $1.00.

❒ **FAMILY ADVOCACY ORGANIZATIONS: ADVANCES IN SUPPORT AND SYSTEM REFORM.** 1993. *Describes and evaluates the development of statewide parent organizations in 15 states.* $8.50.

❒ **FAMILY CAREGIVING FOR CHILDREN WITH A SERIOUS EMOTIONAL DISABILITY.** 1993. *Summarizes a family caregiving model employed in survey of families with children with emotional disabilities. Includes review, questionnaire, data collection and analysis procedures and findings.* $8.00.

❒ **FAMILY INVOLVEMENT IN POLICY MAKING: A FINAL REPORT ON THE FAMILIES IN ACTION PROJECT.** 1995. *Outcomes of focus group life history interviews, five case studies of involvement in policy-making processes, results of survey data, implications for family members and policy-makers.* $10.25.

❒ **FAMILY/PROFESSIONAL COLLABORATION: THE PERSPECTIVE OF THOSE WHO HAVE TRIED.** 1994. *Describes curriculum's strengths and limitations, effect of training on practice, barriers to collaboration.* $7.50.

❒ **FAMILY RESEARCH & DEMONSTRATION SYMPOSIUM REPORT.** 1993. *Summarizes recommendations from 1992 meeting for developing family research and demonstration agenda in areas of parent-professional collaboration, training systems, family support, advocacy, multicultural competence, and financing.* $7.00.

❒ **FAMILY SUPPORT AND DISABILITIES: AN ANNOTATED BIBLIOGRAPHY.** 1995. *Family member relationships with support persons, service system for families, descriptions of specific family support programs.* $6.50.

❒ **GLOSSARY OF ACRONYMS, LAWS, & TERMS FOR PARENTS WHOSE CHILDREN HAVE EMOTIONAL HANDICAPS.** 1994. *Glossary excerpted from Taking Charge. Approximately 150 acronyms, laws, words, phrases explained.* $3.00.

❒ **INTERPROFESSIONAL EDUCATION FOR FAMILY-CENTERED SERVICES: A SURVEY OF INTERPROFESSIONAL/INTERDISCIPLINARY TRAINING PROGRAMS.** 1995. *Planning, implementation, content, administration, evaluation of family-centered training programs for professionals.* $9.00.

❒ **ISSUES IN CULTURALLY COMPETENT SERVICE DELIVERY: AN ANNOTATED BIBLIOGRAPHY.** 1990. $5.00.

❒ **MAKING THE SYSTEM WORK: AN ADVOCACY WORKSHOP FOR PARENTS.** 1987. *A trainers' guide for a one-day workshop to introduce the purpose of advocacy, identify sources of power, the chain of command in agencies and school systems, practice advocacy techniques.* $8.50.

❒ **NATIONAL DIRECTORY OF ORGANIZATIONS SERVING PARENTS OF CHILDREN AND YOUTH WITH EMOTIONAL AND BEHAVIORAL DISORDERS, THIRD EDITION.** 1993. *Includes 612 entries describing organizations that offer support, education, referral, advocacy, and other assistance to parents.* $12.00.

❒ **NEXT STEPS: A NATIONAL FAMILY AGENDA FOR CHILDREN WHO HAVE EMOTIONAL DISORDERS CONFERENCE PROCEEDINGS.** 1990. *Development of parent organizations, building coalitions, family support services, access to educational services, custody relinquishment, case management.* $6.00.

❒ **NEXT STEPS: A NATIONAL FAMILY AGENDA FOR CHILDREN WHO HAVE EMOTIONAL DISORDERS (BOOKLET).** 1991. *Designed for use in educating about children's mental health issues. Single copy.* $2.50. *Five Copies.* $7.00.

❒ **ORGANIZATIONS FOR PARENTS OF CHILDREN WHO HAVE SERIOUS EMOTIONAL DISORDERS: REPORT OF A NATIONAL STUDY.** 1991. *Study of 207 organizations for parents of children with serious emotional disorders.* $4.00.

❒ **PARENT-PROFESSIONAL COLLABORATION CONTENT IN PROFESSIONAL EDUCATION PROGRAMS: A RESEARCH REPORT.** 1990. *Results of nationwide survey of professional programs that involve parent-professional collaboration. Includes descriptions of individual programs.* $5.00.

❒ **PARENTS AS POLICY-MAKERS: A HANDBOOK FOR EFFECTIVE PARTICIPATION.** 1994. *Describes policy-making bodies, examines advocacy skills, describes recruitment methods, provides contacts for further information.* $7.25.

❒ **RESPITE CARE: A KEY INGREDIENT OF FAMILY SUPPORT. 1989 CONFERENCE PROCEEDINGS.** *Starting respite programs, financing services.* $5.50.

❒ **STATEWIDE PARENT ORGANIZATION DEMONSTRATION PROJECT FINAL REPORT.** 1990. *Evaluates the development of parent organizations in five states.* $5.00.

❒ **THE DRIVING FORCE: THE INFLUENCE OF STATEWIDE FAMILY NETWORKS ON FAMILY SUPPORT & SYSTEMS OF CARE.** 1994. *Highlights 1993 activities of 15 statewide family advocacy organizations.* $9.00.

❒ **THERAPEUTIC CASE ADVOCACY TRAINERS' GUIDE: A FORMAT FOR TRAINING DIRECT SERVICE STAFF & ADMINISTRATORS.** 1990. *Addresses interagency collaboration among professionals in task groups to establish comprehensive systems of care for children and their families.* $5.75.

❒ **THERAPEUTIC CASE ADVOCACY WORKERS' HANDBOOK.** 1990. *Companion to the Therapeutic Case Advocacy Trainers' Guide. Explains the Therapeu-*

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tic Case Advocacy model, structure of task groups, group process issues, evaluations. **$4.50.**

❒ **WORKING TOGETHER FOR CHILDREN: AN ANNOTATED BIBLIOGRAPHY ABOUT FAMILY MEMBER PARTICIPATION IN CHILDREN'S MENTAL HEALTH POLICY-MAKING GROUPS.** 1994. *Ideas for enhancing family member participation and conceptual models regarding increasing participation.* **$6.25.**

❒ **WORKING TOGETHER: THE PARENT/PROFESSIONAL PARTNERSHIP.** 1987. *Trainers' guide for a one-day workshop for a combined parent/professional audience.* **$8.50.**

❒ **A COMPLETE LIST OF OTHER PUBLICATIONS AUTHORED BY RESEARCH AND TRAINING CENTER STAFF.** *Lists journal articles, book chapters, monographs.* **Free.** *Also available on the worldwide web: www.rtc.pdx.edu/resource/puborder.htm*

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